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Risk communication, behaviour change and tick-borne disease in the UK

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RISK COMMUNICATION, BEHAVIOUR CHANGE AND TICK-BORNE DISEASE IN THE UK

Submitted by FIONA MARGARET MOWBRAY to King's College London as a thesis for the degree of Doctor of Philosophy in Psychological Medicine, September 2013

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Although I never planned to do a PhD, it seems that maybe it didn't come as such a surprise to my family. I'm pretty sure that they saw it as the logical next step in the educational prospects that they could see for me from the beginning. I was never forced to go down any particular educational route, but I have always enjoyed learning and research and was fortunate to grow up in a household where both of these interests were highly valued and encouraged. Despite now living an ocean away from my parents and technically being a 'proper grown up' they still manage to provide me with every form of support and their belief in my abilities has been a source of encouragement throughout my education.

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Thank you, all!

ABSTRACT

Tick-borne disease represents a growing problem in the UK. While some communications materials exist which encourage members of the public to adopt precautionary behaviours when in tick affected areas, these have not been informed by empirical evidence as to what factors promote uptake of protective behaviours and have not had their effectiveness formally tested.

This research:

- Identified knowledge and perceptions of risk concerning tick-borne disease in the UK that were associated with uptake of health protective behaviours
- Designed new communications materials promoting the uptake of health protective behaviours
- Tested whether the effect of these new materials was improved by also incorporating messages designed to reduce the emotion of disgust

Qualitative interviews allowed understanding of the thought processes of experts and the public with regards to the risk posed by ticks and tick-borne disease. Tick checking emerged as the most effective and accepted protective behaviour. A quantitative survey with members of London-based outdoor groups provided data showing that knowledge, perceived likelihood of being bitten, self-efficacy about tick removal and lower levels of disgust were the strongest predictors of checking behaviour. Both the qualitative and quantitative data fed into the design of communication materials that served as interventions against tick-borne disease risks. These were tested in a pilot randomised controlled trial where members of the public were sent one of three versions of the intervention, one including disgust reduction messages, one with messages based on behaviour change techniques developed from conventional models within health psychology and one with existing messages. The intervention based on conventional theories of health psychology proved most effective at increasing the uptake of tick checking behaviour and disgust reduction appeared to decrease behavioural engagement. Future research is needed to investigate the role of disgust as a driver of behaviour change, while policy makers need to be aware of the importance of engaging with the public and incorporating elements of health psychology theory into intervention design.

TABLE OF CONTENTS

	Page
LIST OF FIGURES	9
LIST OF TABLES	10
 CHAPTER 1: REVIEW OF LITERATURE.....	 11
Introduction.....	11
Methods.....	15
<i>Search strategy for identification of studies</i>	<i>15</i>
<i>Inclusion criteria.....</i>	<i>15</i>
<i>Identifying behaviour change techniques</i>	<i>15</i>
Results.....	16
<i>Search results</i>	<i>16</i>
<i>‘Before and after’ studies</i>	<i>16</i>
<i>Controlled trials.....</i>	<i>20</i>
<i>Behaviour change techniques</i>	<i>23</i>
Discussion	25
<i>Current evidence</i>	<i>25</i>
<i>Predictors of tick protective behaviour</i>	<i>26</i>
<i>Suggestions for future research</i>	<i>32</i>
<i>Improving future research – a role for behaviour change theory?</i>	<i>35</i>
<i>Improving future research – a role for disgust?</i>	<i>35</i>
<i>Improving future research – thesis aims</i>	<i>39</i>
 CHAPTER 2: QUALITATIVE INTERVIEWS	 40
Introduction.....	40
Expert Interviews	42
Methods	42
<i>Design</i>	<i>42</i>
<i>Participants</i>	<i>42</i>
<i>Interview schedule</i>	<i>42</i>
<i>Procedure</i>	<i>43</i>
<i>Analysis</i>	<i>43</i>
Results.....	44
<i>Primary prevention</i>	<i>46</i>
<i>Strategy 1: Wearing long trousers tucked into socks</i>	<i>46</i>
<i>Strategy 2: Wearing light coloured trousers.....</i>	<i>46</i>
<i>Strategy 3: Stick to clear pathways.....</i>	<i>47</i>
<i>Strategy 4: Use of tick repellents.....</i>	<i>47</i>
<i>Knowledge and experience as key behavioural drivers.....</i>	<i>48</i>

<i>Secondary prevention</i>	49
Strategy 1: Performing a tick check	49
Strategy 2: Tick removal.....	50
Strategy 3: Patient symptom awareness	51
Overall attitudes about communication.....	53
<i>Implications for public health messages</i>	54
Public Interviews	56
<i>Methods</i>	56
<i>Design and procedure</i>	56
<i>Participants</i>	56
<i>Analysis</i>	57
<i>Results</i>	57
<i>Primary prevention</i>	60
Experience.....	60
Knowledge and awareness	61
Risk perceptions.....	63
Strategy 1: Wearing long trousers	64
Strategy 2: Tucking trousers into socks	65
Strategy 3: Stick to clear pathways.....	66
Strategy 4: Use of repellent	67
<i>Secondary prevention</i>	69
Experience.....	69
Knowledge	69
Risk perceptions.....	70
Strategy 1: Performing a tick check	70
Strategy 2: Tick removal.....	72
Further strategies: Keep an eye on bite site, visit GP and seek information.....	73
Concerns about GP tick awareness.....	74
Discussion	75
<i>Methodological limitations</i>	79
<i>Links to theory</i>	80
Conclusions	81
 CHAPTER 3: QUANTITATIVE SURVEY	83
Introduction	83
Methods	84
<i>Survey design, ethics and procedure</i>	84
<i>Participants</i>	85
<i>Survey questions</i>	86
<i>Behavioural outcome variable questions</i>	86
<i>Predictor variable questions</i>	87
<i>Knowledge and experience</i>	88
<i>Demographic variables</i>	89
<i>Analyses</i>	89

Results	90
<i>Sample</i>	90
<i>Participant demographics</i>	91
<i>Behavioural reactions: primary outcomes</i>	93
<i>Behavioural reactions: secondary outcomes</i>	97
<i>Background knowledge</i>	98
<i>Association between demographic variables and outcomes</i>	100
<i>Association between psychological variables and outcomes</i>	102
Discussion	107
<i>Links to theory and previous studies</i>	107
<i>Methodological limitations</i>	110
<i>Implications for communication</i>	112
Conclusions	112
 CHAPTER 4: INTERVENTION DESIGN	114
Introduction	114
Development of the Control Intervention	115
Initial Development of Intervention Based on Conventional Models within Health Psychology	121
Initial Development of Disgust Reduction Intervention	126
Intervention Piloting and Read Aloud Protocol	129
<i>Methods</i>	129
<i>Design</i>	129
<i>Participants</i>	129
<i>Procedure</i>	129
<i>Analysis</i>	130
<i>Results</i>	130
<i>First round of interviews</i>	130
<i>Review by topic expert</i>	133
<i>Second round of interviews</i>	133
<i>Summary of changes made as a result of piloting</i>	135
Discussion	138
<i>Links to previous research</i>	138
<i>Strengths and weaknesses</i>	139
 CHAPTER 5: PILOT RANDOMISED CONTROLLED TRIAL	142
Introduction	142
Methods	143

<i>Design</i>	143
<i>Ethics</i>	144
<i>Procedure</i>	144
<i>Sample</i>	145
<i>Participants</i>	145
<i>Survey questions</i>	146
<i>Behavioural outcome variable questions</i>	146
<i>Predictor variable questions</i>	147
<i>Knowledge and experience</i>	149
<i>Demographic variables</i>	149
<i>Analyses</i>	149
Results	150
<i>Aim 1: Participant retention</i>	150
<i>Aim 2: Effectiveness of variables and scales</i>	153
<i>Aim 3: Intervention effectiveness and sample size calculation</i>	153
<i>Participant demographics</i>	153
<i>Uptake of tick checking behaviour</i>	156
<i>Assessment of interventions (predictor variables)</i>	158
<i>Assessment of interventions (secondary outcomes)</i>	160
<i>Aim 4: Intervention feedback</i>	163
<i>Aim 5: Test the effectiveness of Select Survey for delivering the pilot RCT</i>	167
Discussion	167
<i>Limitations and strengths</i>	169
<i>Implications for communication</i>	171
 CHAPTER 6: DISCUSSION AND CONCLUSIONS	173
 Summary of Findings	173
<i>Aim 1: Identify interventions that effectively increase protective behaviour</i>	173
<i>Aim 2: Identify knowledge and perceptions of tick-borne disease in the UK</i>	174
<i>Aim 3: Identify driver of and barriers to tick protective behaviour</i>	174
<i>Aim 4: Determine which factors are most strongly associated with the uptake of protective behaviours</i>	175
<i>Aim 5: Design and preliminarily test the effectiveness of communication materials at increasing the uptake of protective behaviours</i>	175
<i>Aim 6: Determine the sample size for a full RCT</i>	176
Implications	176
<i>Implications for future research</i>	176
<i>Links for theory</i>	179
<i>Use of health psychology and behaviour change theories</i>	179
<i>Use of mental models</i>	180
<i>Disgust</i>	181
<i>Implications for practice and policy</i>	183
 Strengths and Limitations	185

Critical Reflection	187
Key Recommendations	189
Conclusions	190
 REFERENCES.....	 192
 APPENDICES.....	 203
Appendix 1: <i>Literature review search strategy</i>	203
Appendix 2: <i>Behaviour change techniques taxonomy.....</i>	206
Appendix 3: <i>Expert interview schedule</i>	210
Appendix 4: <i>Public interview schedule.....</i>	211
Appendix 5: <i>Web survey questions</i>	213
Appendix 6: <i>Web survey psychological variable score</i>	218
Appendix 7: <i>Demographics and tick check of clothes.....</i>	218
Appendix 8: <i>Demographics and tick check of body</i>	220
Appendix 9: <i>Demographics and trousers.....</i>	221
Appendix 10: <i>Demographics and light coloured trousers.....</i>	222
Appendix 11: <i>Demographics and tucking trousers into socks</i>	223
Appendix 12: <i>Demographics and sticking to clear pathways</i>	224
Appendix 13: <i>Demographics and repellent on clothes</i>	225
Appendix 14: <i>Demographics and repellent on skin</i>	226
Appendix 15: <i>Predictor variables and trousers</i>	227
Appendix 16: <i>Predictor variables and light coloured trousers.....</i>	228
Appendix 17: <i>Predictor variables and tucking trousers into socks</i>	229
Appendix 18: <i>Predictor variables and sticking to clear pathways</i>	230
Appendix 19: <i>Predictor variables and repellent on clothes</i>	231
Appendix 20: <i>Predictor variables and repellent on skin</i>	232
Appendix 21: <i>New Forest leaflet.....</i>	233
Appendix 22: <i>Royal Parks leaflet</i>	234
Appendix 23: <i>Read aloud discussion guide</i>	235
Appendix 24: <i>Pilot RCT questionnaire</i>	237
Appendix 25: <i>PHE tick leaflets</i>	248
Appendix 26: <i>Letter of support</i>	249

LIST OF FIGURES

Figure	Page
Figure 2.1 <i>Expert mental model</i>	45
Figure 2.2 <i>Erythema migrans rash</i>	51
Figure 2.3 <i>Public mental model part 1</i>	58
Figure 2.4 <i>Public mental model part 2</i>	59
Figure 3.1 <i>Tick image identification question options</i>	88
Figure 3.2 <i>Have you ever been bitten by a tick?</i>	93
Figure 3.3 <i>Tick check of clothes while walking</i>	94
Figure 3.4 <i>Tick check of body while walking</i>	94
Figure 3.5 <i>Tick check of body after walking</i>	94
Figure 3.6 <i>Reasons participants did not check for ticks</i>	95
Figure 3.7 <i>Areas of body checked and how</i>	96
Figure 3.8 <i>Precautionary behaviours to avoid ticks</i>	97
Figure 3.9 <i>Tick identification</i>	98
Figure 3.10 <i>Tick removal methods</i>	99
Figure 4.1 <i>Control intervention</i>	119
Figure 4.2 <i>First experimental intervention</i>	136
Figure 4.3 <i>Second experimental intervention</i>	137
Figure 5.1 <i>Participant drop-out by group</i>	152
Figure 5.2 <i>Information reassurance</i>	163
Figure 5.3 <i>Information confidence</i>	164
Figure 5.4 <i>Information awareness</i>	164
Figure 5.5 <i>Information usefulness</i>	164
Figure 5.6 <i>Information clarity</i>	165
Figure 5.7 <i>Enough information</i>	165
Figure 5.8 <i>Outdoor avoidance</i>	166

LIST OF TABLES

Table	Page
Table 1.1 <i>Before and after studies</i>	17
Table 1.2 <i>Controlled trials</i>	19
Table 1.3 <i>Studies identifying predictors of tick protective behaviours</i>	28
Table 3.1 <i>Participant demographics</i>	90
Table 3.2 <i>Associations between demographic variables and tick checking behaviour</i>	99
Table 3.3 <i>Predictor scales reliability</i>	100
Table 3.4 <i>Logistic regression predicting tick checking behaviour after walking</i>	101
Table 3.5 <i>Logistic regression predicting tick checking behaviour of the body while walking</i>	103
Table 3.6 <i>Logistic regression predicting tick checking behaviour of the clothes while walking</i>	104
Table 4.1 <i>Control leaflet comparison</i>	113
Table 4.2 <i>Inclusion justification for intervention based on models of health psychology</i>	119
Table 4.3 <i>Inclusion justification for disgust reduction intervention</i>	124
Table 5.1 <i>Participant demographics by group</i>	153
Table 5.2 <i>Tick checking by intervention group</i>	155
Table 5.3 <i>Sample sizes by intervention effect size</i>	155
Table 5.4 <i>Full scale RCT recruitment</i>	156
Table 5.5 <i>Difference in intervention conditions by time and predictor variables</i>	157
Table 5.6 <i>Wearing long trousers by intervention group</i>	158
Table 5.7 <i>Wearing light coloured trousers by intervention group</i>	159
Table 5.8 <i>Tucking trousers into socks by intervention group</i>	159
Table 5.9 <i>Sticking to clear pathways by intervention group</i>	160
Table 5.10 <i>Using repellent on clothes by intervention group</i>	160
Table 5.11 <i>Using repellent on skin by intervention group</i>	161
Table 5.12 <i>Intervention feedback by group</i>	166
Table 5.13 <i>Time spent on leaflet by group</i>	167

CHAPTER 1: REVIEW OF LITERATURE

Introduction

This PhD began in October 2010 and was equally funded by King's College London and the Health Protection Agency (now Public Health England). Part of the Health Protection Agency's remit was to protect the UK public from new or emerging health threats, including infectious and vector-borne disease. In April 2013 the Health Protection Agency became part of Public Health England, a government-led service that brings together a wide range of public health specialists whose aim is to protect and improve the nation's health. This PhD research was undertaken with the overall objective of contributing to the future reduction in tick-borne disease through the design and testing of communication materials to increase the uptake of tick protective behaviours. Regardless of the organizational changes that occurred during the lifetime of this PhD, the aims of the work still address the overall remit to improve and protect the health of the UK population.

In light of the increased spread of Lyme borreliosis in peri-urban areas in the United Kingdom (UK), the sudden emergence of chikungunya virus in Italy in 2007 and the recent outbreak of bluetongue virus transmitted by midges in northern Europe, there is a need for increased public awareness related to vector-borne diseases in the UK (Chretien & Linthicum, 2007). A vector is an agent that transmits disease to another living organism, with common vectors including mosquitos and ticks. Indeed, tick-borne disease represents a growing problem in the UK. Ticks are small arachnids which act as vectors for the disease by obtaining the bacteria from infected mammals and birds that act as reservoir hosts and spreading it to other mammals and birds that they subsequently bite. They are most active during the late spring and early summer, but are around into the autumn months throughout the UK (Public Health England [PHE], 2012). Lyme disease is the most common tick-borne disease in the UK and often presents with a distinctive erythema migrans, or bulls-eye shaped rash, and flu-like symptoms (PHE, 2012). Lyme disease generally responds well to antibiotics at all stages of infection; however more serious problems such as viral-like meningitis, facial palsy, nerve damage and arthritis do sometimes occur and can be difficult to diagnose and treat (Rizzoli et al., 2011). Since 1996 the UK has had an enhanced surveillance system for monitoring cases of Lyme disease. Although the disease is not statutorily notifiable, all cases are referred to Public Health England's Lyme Borreliosis Unit for laboratory confirmation of diagnosis (PHE, 2012). This reporting system has evidenced the increase in the incidence of Lyme disease showing that in 2001 there were 268 reported cases versus 905 cases in 2010 (PHE, 2012). These

increases are in line with those documented in Europe over the past decade (Hofhuis et al., 2006). Although this rise in cases is likely to be driven by factors such as increased awareness of the disease and better diagnostic testing methods, it has also been influenced by increases in the population of tick species that transmit the disease and an increase in popularity of recreation based holidays (PHE, 2012). In addition, there are likely to be climate driven changes to the geographic distribution, density and activity of the tick species that act as a vector for the bacteria that cause Lyme disease (Medlock et al., 2013).

Public health education is a key intervention against infectious diseases and has proven effective in reducing the incidence of tick-borne encephalitis, dengue and malaria in other parts of the world (Hung et al., 2002). Understanding current levels of knowledge, perceptions of risk and likely behavioural responses is crucial to the success of such campaigns (Williams, Collins, Bauaze, & Edgeworth, 2010; Setbon & Raude, 2009).

Following its discovery in the late 1970s, Lyme disease has become the most common tick-borne disease in both North America and Europe (de Vries & van Dillen, 2002), although tick-borne encephalitis (TBE) and Crimean-Congo Haemorrhagic Fever (CCHF) are both also prevalent in parts of Europe. Studies have shown that improved knowledge of the basic protective behaviours that can be taken to reduce tick bites may decrease the risk of tick-borne disease (Ergonul, 2006; Mead, 2011). Certainly in the case of Lyme disease, our understanding of the tick vector life cycle and the effectiveness of prevention strategies should make it a preventable illness, yet the incidence of the disease continues to increase (Corapi et al., 2007).

Low uptake of protective behaviours among the general public lies at the heart of this problem. Observational studies conducted in areas with endemic tick-borne disease repeatedly find that a large proportion of people fail to take even the most basic of precautions such as wearing long trousers, using repellent or avoiding locations of highest risk (Herrington et al., 1997; Phillips et al., 2001), a finding echoed in national surveys (Herrington, 2004). Self reported checking for ticks after potential exposure is also low despite the fact that removal of a tick within 24 hours may effectively prevent transmission of the bacteria and infection (Mawby & Lovett, 1998). In light of the low level of protective behaviours among the general public, various initiatives have been attempted to improve their uptake. For example, the European Centre for Disease Control (ECDC) has produced a communication toolkit on tick-borne diseases including templates that can be adapted to fit the needs of particular countries (http://www.ecdc.europa.eu/en/healthtopics/tick_borne_diseases/public_health_measures/P

ages/communication_toolkit.aspx), the Center for Disease Control (CDC) in America has developed a series of resources which include educational materials for both the public and medical professionals (http://www.cdc.gov/ncidod/dvbid/lyme/ld_resources.htm), while in the UK various materials have also been produced by official agencies (for example, http://www.hpa.org.uk/web/HPAwebFile/HPAweb_C/1271256716650). Not all materials that are put into the public domain have been evaluated, however. This is concerning, as previous attempts to provide the public with information materials about health threats have not always been a success. Indeed, on occasion such attempts may even have detrimental effects (e.g. McKenna & Williams, 1993; Glik, Drury, Cavanaugh, & Shoaf, 2008; Gould et al.; 2007).

One way to increase the chances of public education campaigns succeeding is to ensure that they are well grounded in empirically tested psychological theories of behaviour change. A number of such theories exist which propose different factors that may drive behaviour change. Although numerous theories exist, many of their components are similar. The theory of planned behaviour (Ajzen, 1991), for example, suggests that a given behaviour is likely to occur if a person is confident that they can effectively perform the behaviour, has a favourable attitude towards the desired behaviour and believes that others would view them positively if they engaged in that behaviour (Conner & Sparks, 2005).

A similar approach is the 'health belief model'. Perceptions of the individual are again central to this model which posits that an individual's beliefs about their own susceptibility to a health threat, their perceptions about the severity of that threat and their perceptions about the benefits and barriers associated with a particular protective action will determine whether they adopt that action. Extensions to the model suggest that an individual's 'self-efficacy' (their belief in their own ability to perform a given behaviour) also play a strong role in determining whether a behaviour is adopted, as does the existence of cues to action that prompt or remind someone to engage in the behaviour (see, for example, Abraham & Sheeran, 2005).

Social cognitive theory identifies behaviour as an interaction between personal, behavioural and environmental factors, but explains that the components of self efficacy, outcome expectancies and impediments and facilitators all work together to influence behaviour (Luszczynska & Schwarzer, 2005). Outcome expectancies are the beliefs that people hold regarding whether the suggested behaviour change will be effective and worthwhile. Similar to the benefits and barriers outlined in the health belief model, the concepts of impediments and facilitators relate to factors that might encourage or discourage a desired behaviour.

Protection motivation theory has been used both as a framework for the development and evaluation of persuasive communication as well as a model for predicting health behaviour (Rogers, 1975). A threat appraisal is formed by an individual based on their perceived likelihood of a particular event occurring and the perceived severity of the event (Rogers, 1975). The way in which an individual chooses to respond to a threatening situation is termed their coping appraisal and is based on both the belief that uptake of a recommended behaviour will resolve the threat (response efficacy) and an individual's belief in their own ability to effectively perform the behaviour (self efficacy) (Cameron, 2009).

These four theories do not provide an exhaustive list of all theories of behaviour change. However, while several psychological theories exist which could be used to inform campaigns designed to improve uptake of behaviours which protect against tick-borne disease, the extent to which these theories have been used in practice is unclear. Equally, it is possible that other factors unique to tick-borne disease may play a role in determining whether people adopt appropriate protective behaviours. I conducted a systematic review of all previous studies that have assessed the impact of educational or behavioural interventions on uptake of behaviours intended to protect against tick-borne disease. My aim was to assess the state of the art in this field, and to identify those interventions which have been shown to improve the use of protective behaviours.

In addition to performing a standard systematic review, I also completed a behaviour change techniques analysis of the studies included in the review. The availability of a taxonomy of behaviour change techniques should help to standardise intervention descriptions making them clearly and easily understood and replicable (Abraham & Michie, 2008). A list of behavioural change techniques has been developed by Abraham and Michie (2008) and includes 26 techniques drawn from textbook consultation and brainstorming. The taxonomy has been tested for reliability and while the authors explain that the taxonomy is not an exhaustive list of all intervention techniques, it does provide a starting point to allow for further development.

Methods

Search strategy for the identification of studies

I searched the following electronic databases from inception to December 2010 for potentially relevant studies: ISI Web of Knowledge, Medline, PsycINFO, Embase and Scopus. These were searched for papers containing MeSH terms or keywords relating to tick-borne diseases such as “tick” or “Lyme” and also containing MeSH terms or keywords relating to behavioural interventions for example, “risk communication,” “campaign,” “poster” or “leaflet.” The full search is available in appendix 1. In addition, I examined the reference sections of any pertinent studies and reviews for other references. As a check for completeness, I also discussed our review with 13 experts in tick-borne diseases and asked them to suggest any other published or unpublished material that I might have missed. These experts were from a range of specialties including entomology, public health epidemiology, ecology, land management, deer management, parasitology and public health sciences.

Inclusion criteria

Eligible studies needed to contain data concerning the impact of any communications-based public health intervention which was aimed at preventing tick-borne disease. I excluded research that assessed knowledge, attitudes and behaviours about tick-borne disease but which did not test the efficacy of an intervention strategy. I included both efficacy and effectiveness studies. Any study design was acceptable for inclusion.

Identifying behaviour change techniques

The existing taxonomy (see appendix 2) was applied to the 9 studies examined in this literature review to determine which techniques have been tested regarding tick-borne disease. The taxonomy is meant to be applied to the description of an intervention as provided by the authors of the study in their methods section (Abraham & Michie, 2008). For each study the intervention description was assessed and compared against the taxonomy to determine which of the behaviour change techniques were evident within the intervention strategy.

Results

Search results

In total, approximately 1800 titles or abstracts were examined from which 386 papers were selected as potentially relevant to the review. Of these, 208 were excluded because they were editorials or duplicate publications. A further 169 were reviews or educational materials targeted towards health professionals. Details relating to nine individual studies were included. Of these, five had a 'before and after' design, four of which assessed the effectiveness of an educational intervention and one of which assessed the mode of communication. The other four studies were controlled trials of educational interventions.

'Before and after' studies

Table 1.1 provides a summary of the before and after studies that I identified.

Table 1.1 Behavioural intervention studies for tick-borne disease – before and after studies

Reference	Design, sample and country	Intervention	Procedure	Outcomes examined and effect of intervention (significant effects in bold, no significant effect unless stated otherwise, effect sizes given for significant effects where known)
Fox, 2008	Before and after. 56 children, aged 8 to 10 years old. US.	Two to four sessions (180min in total) about ticks and LD, using videos and interactive work books.	Questionnaires given pre (t1) and post (t2) intervention.	Twelve items of knowledge or protective behaviour, or which two are noted as significantly different at t2: I know how to wear clothing that will make it easier to find ticks and I need help to find ticks on my body .
Gould, 2008	Before and after. New, random samples of approx. 400 people selected at each time point from three geographical regions (r1, r2 and r3). US.	“Intensive education campaigns [using] a multitude of diverse educational methods, including billboards, flyers, newspaper articles, presentations etc.” Interventions stressed use of protective behaviours.	Telephone interviews administered just before the campaign (t1) two to three years later (t2) and, for r1, five years later (t3)	Knowing “a lot” or “some” about LD (improved in r1 at t3, p=0.05; reduced in r2 at t2, p=0.004, improved in r3 at t2, p=0.004). Perceived severity of, and likelihood of getting LD (reduced likelihood in r2 at t2 p=0.003, increased likelihood in r3 at t2, p=0.0002). Reporting avoiding wooded areas (decreased in r2, p=0.02; decreased in r3 p=0.003), tucking pants into socks (decreased in r2, p<0.001), performing tick checks (increased in r3, p=0.02) or using repellent (increased in r3, p<0.001). Using environmental control of ticks by: spraying pesticide (improved in r1 at t2, p<0.001), removing brush of leaf litter (improved in r1 at t2, p<0.001), using wood chip or gravel borders (improved in r1 at t2, p<0.001), keeping deer out of property (improved in r1 at t2, p<0.001). Being willing to spend at least \$100 on tick control (increased in r3 at t2, p=0.002). Approving of community efforts to reduce deer population, provide information, use pesticides on deer or use pesticides.
Gray, 1998	Before and after. 31 Irish agriculture students, 11 Irish biology students, 75 British biology students. UK and Ireland.	LD Information leaflet or lecture containing the same information as in the leaflet.	Questionnaire given “before and a week after issue of the leaflet.”	Four questions on: have you ever heard of a tick, have you heard of LD, do ticks transmit LD, does LD occur in this country? (knowledge improved for all four items in each sample, no statistical test reported).
Jenks, 2005	Before and after. 40 recent immigrants to the USA, attending a primary health clinic. US.	One to one education by a physician covering basic facts about LD. Take-home education sheet on LD recognition and prevention.	Brief questionnaire pre-intervention and 2.3 months later.	Identification of Lyme Disease (LD) rash, knowing that ticks transmit LD, knowing that engorged ticks are more dangerous and knowing how to remove a tick (knowledge improved for all four items, p<0.001).
Maher, 2004	Before and after. 295 children aged 8 to 12. US.	“Fun and interactive” programme teaching children “how to protect themselves against ticks and to do effective checks.”	“A questionnaire was administered before and after the intervention.”	Knowledge of how a tick gets on you (p<0.0001), how long a tick has to be attached to transmit LD (p<0.0001) and how to find a tick on self (p<0.0003) all improved post intervention. Frequency of tick checking (p=0.02) and childrens’ confidence in ability to find a tick (p=0.04) improved. No effect on feeling it is easier to remember to do tick checks.

LD = Lyme Disease

A study of Connecticut residents tested the effectiveness of an intensive community-based intervention designed to increase awareness of Lyme disease and, through this, to increase the uptake of prevention behaviours (Gould et al., 2008). Three locations with endemic Lyme disease were involved, each of which developed their own educational campaign. At pre-test each community had similar baseline levels of knowledge, attitudes and behaviour regarding ticks and Lyme. Two years after the campaigns the survey was administered again. The effects of the campaigns showed important differences between the three regions. In two regions, people were more likely to report increased knowledge, feeling more at risk and being more likely to engage in activities such as performing tick checks, using repellent, or spraying pesticide in outside areas. In one region the campaign appeared counter-productive, reducing knowledge and decreasing perceptions about the likelihood of catching the disease. No description was included regarding the actual interventions developed and implemented at each of the three locations. This makes it difficult to assess why the differences occurred, but the authors speculated that it could have reflected decreased personal preference regarding the recommended protective behaviours or that it could be a result of the relative emphasis placed on these behaviours by each area's education programme.

A study in New York State explored the effectiveness of an educational intervention among an immigrant population (Jenks & Trapasso, 2005). This population was at particular risk of contracting a tick-borne disease because of the outdoor nature of their work and because Lyme is not endemic in their countries of origin, meaning that awareness of the disease was low. Eighty participants were recruited from a community health centre and asked four questions about ticks and Lyme disease. Participants then discussed their answers with a clinician, who also provided basic information about Lyme disease and gave them a take home information sheet. One to three months later, participants who returned to the clinic for routine appointments (n=40) completed the same test. Prior to the intervention none of the participants were aware of Lyme disease or able to identify its distinctive erythema migrans rash. Following the intervention, all were able to do so. Unfortunately, the lack of any control group for this study makes it difficult to assess the effectiveness of the intervention. In addition, it is likely that a non-response bias may have artificially inflated the apparent efficacy of the intervention, with participants who were less interested in their health being less likely to attend the clinic on both occasions and complete the study.

During the 1990s, the European Concerted Action on Lyme Borreliosis (EUCALB) was formed with members from across Europe. EUCALB developed a new leaflet about tick-borne disease

and a questionnaire to assess levels of Lyme awareness (Gray et al., 1998). Three groups of British and Irish agriculture and biology students completed the questionnaire and were then provided with the leaflet (two groups) or a lecture based on the leaflet's contents (one group). The questionnaire was completed again one week later. Results indicated a marked improvement in awareness following the intervention. No attempt was made to assess use of protective behaviours, however. The choice of sample also makes it difficult to generalise from the results, as agriculture and biology students may be more interested in tick-borne disease than the general public, have different levels of existing knowledge to draw on when interpreting new information and be more used to being tested on information that they are given.

Fox (2009) studied 56 eight, nine and ten year olds to test whether an educational curriculum provided in written, verbal and video form could improve knowledge of Lyme disease or prevention behaviour. A pre-test showed little or no knowledge of Lyme disease or prevention, but 70% responded that they 'often' or 'sometimes' practiced protective behaviours. The post test, conducted 7 to 10 days later, showed that children reported being significantly more likely to know which clothing to wear to make ticks visible and that they needed the help of an adult to remove a tick. There was some decrease in reports of performance of preventive behaviours, indicating that the intervention may also have had a negative effect, but this was not significant.

The final before and after study also evaluated the effectiveness of an educational intervention in changing knowledge, attitudes and behaviours among children (Maher et al., 2004). School children between the ages of eight and ten years were recruited from four elementary schools within a Lyme endemic area. The intervention was a fun and interactive curriculum focused on how participants could protect themselves from ticks and perform effective tick checking behaviour. All 295 participants completed the same questionnaire before and after the intervention. Children reported a significant increase in the frequency of performing tick checks with confidence in their ability to find a tick on themselves also increasing. Overall, the researchers reported that their intervention increased knowledge, attitudes and precautionary behaviours among children. However, because the study was published as a poster abstract the methodology was not entirely clear. There was no indication of the follow up period or for how long these apparently beneficial effects persisted.

Controlled trials

Methodological details relating to the four controlled trials are given in table 1.2.

The first, by Lawless, Brown and Cartter (1997) used an instructional video with a mock horror movie theme to improve knowledge, attitudes, and behaviours towards Lyme disease prevention among 13-16 year olds from four Connecticut towns. Participants were randomly assigned to intervention groups who viewed the video or control groups who received no intervention. All participants completed a questionnaire to assess their knowledge, attitudes, and behaviours prior to the intervention. One month and 6 months after the video, knowledge had increased significantly in the intervention group but not in the control group. Although intervention group knowledge had decreased by the 6 month follow up, it remained higher than in the control group. While there was some increase in self-reported protective measures such as wearing trousers tucked into socks and avoidance of stone walls during the initial post-intervention test, no significant self-reported behaviour changes were evident at the six month follow up.

In 1998, the Food and Drug Administration of the United States licensed a vaccine for Lyme disease. Delivered over time through three separate injections, the vaccine was eventually removed from the market in 2002 due to poor demand (Nolan & Mauer, 2006). In 1999, the New York State Department of Health offered the vaccine to employees considered at occupational risk of contracting Lyme and a study was undertaken to assess the factors which affected employee decisions to accept or decline the vaccine. Eligible employees were asked to attend an education session where they were given information about Lyme disease and the vaccine. Of the 190 eligible employees, 43% chose to attend the education session while the remaining 57% received the information by mail. Given the nature of their employment, 74% of participants were male; however the majority of those who attended the education session were female. Overall, only 30 participants decided to have the vaccine. Vaccine uptake did not differ significantly between the session participants and those who received the information by mail. Both groups had roughly the same level of knowledge about vaccination pre-intervention, but post-intervention knowledge significantly improved only among the education session participants. It is difficult to draw any conclusions from this study regarding the merits of in-person versus postal information, however, given that participants themselves chose whether to attend the education session, with attendance probably reflecting pre-existing interest in Lyme disease and / or vaccination.

Table 1.2 Behavioural intervention studies for tick-borne disease – controlled trials

Reference	Design, sample and country	Intervention	Procedure	Outcomes examined and effect of intervention (significant effects in bold, no significant effect unless stated otherwise, effect sizes given for significant effects where known)
Daltroy, 2007	Cluster RCT. 13,562 intervention and 16,602 control participants, recruited on ferries to Lyme-endemic island. US.	15min show about severity and likelihood of LD, benefits of preventive behaviours, practice of removal, and take home material. Similar intervention for controls, but about bike safety.	A questionnaire delivered two months after the intervention.	Self-reported tick-borne illness (TBI) among long-term visitors to the island (lower, $p<0.05$), self-reported TBI among short term visitors, self-reported TBI among residents of the island, taking precautions (use of repellent, protective clothing or limit time in tick areas) (reported every day or most days: intervention 58% of participants, control 39%, $p<0.0001$), checking self for ticks (reported every day or most days: intervention 51%, control 37%, $p<0.001$), amount of time spent in tick-affected areas.
Lawless, 1997	Cluster RCT. 142 intervention and 111 control participants, all school children. US.	16min 'mock horror' education video. No intervention for control participants.	A questionnaire administered pre-intervention (t1), 1 month post-intervention (t2) and 6 months after intervention (t3)	Knowledge (better at t2 (mean difference 4.17 on a 12 point scale, $p<0.05$) and t3 (md = 0.98, $p<0.05$)), attitudes (better at t2 (md =0.17 on a 4 point scale, $p<0.001$)), avoid people with LD, use flea and tick collars, look for insects on pets, wear pants tucked into socks (more likely at t2 and t3, $p<0.05$), check self for ticks, use insecticide on skin (more likely at t2, $p<0.05$), use spray in yard (more likely at t2 and t3, $p<0.05$), avoid woods, change clothes, have someone else check for ticks (more likely at t2 and t3, $p<0.05$), avoid woodlands, avoid stone walls (more likely at t2, $p<0.05$), avoid squirrels, avoid farm animals, avoid wooded areas, use alcohol to remove ticks, squeeze to remove ticks (more likely at t2, $p<0.05$), grasp to remove ticks, use spray to remove ticks (more likely at t2 and t3, $p<0.01$), taking actions in past year to prevent Lyme Disease (LD) (more likely at t2 and t3)
Malouin, 2003	RCT. 148 intervention and 169 control participants, randomly selected from an endemic area. US.	Ten mailings over five months with information about ticks and LD, reminders, insect repellent samples, tweezers, t-shirts. Similar material for control group, but related to diet, dental health or UV light.	Questionnaires and blood samples before (t1), during (t2) and after (t3) the mailings	Three items of knowledge, including knowing the amount of time needed for transmission of LD (better knowledge at t2 and t3, $p<0.01$). Seventeen items relating to knowledge of and reported performance of tick checks, including checking at home (better knowledge t2 and t3, $p<0.05$) and using a mirror to check (better knowledge t2 and t3; $p<0.01$). Eight items on knowledge of and use of repellents and acaricides (of which five better at t1 and t2, $p<0.01$). "Overall, the data provided little evidence that change in [knowledge, attitude or behaviour] was associated with change in anti-recombinant tick calreticulin antibody.
Nolan, 2006	Controlled trial with self-allocation to conditions. 81 intervention and 109 control participants, all employees at risk of exposure to TBI. US.	In person education session focusing on nature of LD and LD vaccine. Similar information in control condition, but in written format delivered by post.	Telephone interviews pre-education (t1), after second dose of vaccine given (t2) and after third dose (t3)	Five items of knowledge about the vaccine (all more likely to be correct in the intervention group), vaccine uptake.

RCT = randomised controlled trial; LD = Lyme Disease; TBI = Tick-borne Infection; UV = ultraviolet

Another study investigating the effectiveness of an educational intervention aimed at increasing precautionary behaviours regarding tick-borne disease was carried out in the Lyme endemic area of Nantucket Island, Maryland first as a pilot study (Daltroy, Phillips, Shadick, & Wright, 1998) and then as a full scale randomised controlled trial (Daltroy et al., 2007). Over 30,000 passengers on ferry boats to the island over three consecutive summers were randomised into either the control or experimental group. Controls received education about bike safety, while intervention participants received information on preventing tick-borne disease, particularly Lyme disease. Information was delivered on board each boat by entertainers hired to make the messages more compelling. The entertainers also spent time demonstrating and modelling tick removal behaviours and allowing participants to practice the removal process. The theory behind the presentation and the hands-on interaction was to relate existing health protection behaviours such as applying sun cream or checking the body for moles to new tick prevention behaviours such as applying tick repellent or checking the body for ticks. Before leaving the boat, participants were given materials such as a pamphlet on Lyme disease, a map of tick hot spots on the island, coupons for tick repellent and removal tools, and a card showing the actual size of the ticks. Two months after the intervention, all participants were sent a follow-up questionnaire asking them about any occurrence of tick-borne infection, preventive behaviours while on the island and any visits to their primary care physician. No overall significant difference was detected in the self report of tick-borne illness between the experimental or control participants, although there was evidence of lower rates of illness among the subgroup of participants classed as long-term visitors to the island. Nonetheless, experimental participants were more likely than controls to adopt precautionary behaviours as well as to check themselves daily for ticks.

A study conducted in a different Lyme endemic area of Maryland went further than other studies by trying to determine whether the implementation of an educational intervention could actually reduce the incidence of objectively assessed tick bites among the study sample (Malouin et al., 2003). Participants were first selected from the region using random digit dialling before being randomly assigned to either the intervention or comparison group while matching for age, gender and zip code. All participants received materials by mail every 2 weeks between April and September 1999, for a total of 10 mailings. Participants also received and completed a monthly survey of their preventive behaviours. For the intervention group, the mailings included material such as a Lyme disease brochure and tick repellent sample. The control group received a variety of non-tick related materials such as a brochure about exercise and fitness and a toothpaste sample. All participants were asked to attend a

clinic on three occasions to have their blood tested for the presence of antibodies which signal a tick bite. At each visit participants completed a questionnaire to assess their knowledge, attitudes and behaviours towards ticks and Lyme disease. A difference between the intervention and control groups was shown over time in terms of knowledge, positive attitudes towards repellents and the self reported use of the prevention methods; however this was not associated with any change in the serological samples. Entomologists reported that there had been low tick activity due to a very dry summer, so it is possible that this could account for the lack of change in serological samples. The most significant changes in knowledge, attitudes and prevention occurred between the first and second visits to the clinic. These changes coincided with the receipt of the majority of intervention messages and were also at the time of year when people would have been most engaged in some sort of outdoor activity. It is noteworthy that the intervention may have removed some barriers to adoption of repellent use by providing free samples, but that this removal would have been only temporary; it is possible that the inconvenience of having to actively acquire and pay for any further repellent may result in a future drop in usage even if attitudes remain positive.

Behaviour change techniques

The study by Gould et al. (2008) provided little in the way of intervention description making it difficult to pinpoint particular behaviour change techniques. It is obvious that the intervention provided participants with information; however from the description provided in the article it is impossible to say accurately whether this was information linking behaviour to health, on consequences of performing the behaviour or about others' approval regarding the behaviour. One aspect of the intervention in this study involved talking to groups of people about ticks and tick prevention, so it is likely that the techniques of providing instruction about how to perform recommended behaviours, providing general encouragement and modelling or demonstrating those behaviours were used. Finally, information provision in a group setting likely also provided the opportunity for social comparison of behaviour performance.

A 2005 study by Jenks and Trapasso focussed on increasing knowledge of ticks and Lyme disease among an immigrant population as a way to encourage participants to adopt precautionary behaviour. General information was provided to participants about the link between behaviours and health and the consequences of performing precautionary behaviours. Following a test designed to gauge tick and Lyme disease knowledge, participants spent one-on-one time with a health practitioner who went through the test and talked to them about the topic. During this time participants would most likely have been told about

the behaviours they could perform in order to avoid ticks and were given feedback about their performance.

Similar to the Jenks and Trapasso (2005) study, Gray et al., (1998) produced a test and a leaflet to increase knowledge and awareness of ticks and Lyme disease as a way of encouraging appropriate behaviour changes. The leaflet intervention gives some general information about how health and tick protective behaviours are linked as well as information about the consequences of performing recommended behaviours. There is also instruction provided about the correct performance of behaviours, particularly tick removal procedures.

Fox (2009) tested a curriculum aimed at increasing knowledge and awareness of Lyme disease among children as well as increasing the practice of tick protective behaviours. The intervention involved general information on the behaviour-health link as well as more specific information about others' approval of the behaviours, particularly parental approval. Participants were given general encouragement motivating them to perform the behaviours and the class setting allowed for the instruction and modelling of behaviours. Children were taught to perform behaviours after exposure to particular environments and were able to compare their behaviour to classmates. Plans for social support were also put in place by encouraging children to seek help from their parents in performing behaviours.

Because the information about the Maher et al., (2004) study was only available in the form of a conference abstract there was limited information about the intervention, although it did seem clear that at least general information about ticks and Lyme disease would have been provided. As with the Fox (2009) study, the participants here were children and the intervention was provided in a classroom setting so it seems likely that general encouragement, the provision of instruction and demonstrations of behaviour would all have been present. There may also have been opportunities for social comparison and support; however this was not obvious from the description.

The Lawless et al., (1997) study used a video to teach teenagers about ticks and Lyme disease and the various prevention behaviours. This video provided general information about the behaviour health link, but it is possible that it may have given information about behaviour consequences as well. Participants would have received instruction from the video about how to perform the recommended behaviours as well as a demonstration of the behaviours.

Nolan and Mauer (2006) conducted a study on the uptake of Lyme disease vaccine among professionals classed as occupationally at risk of contracting the disease. The information they

provided was either through an optional seminar on Lyme disease and the vaccine or in the form of printed information. Once again, general behaviour health link information as well as behaviour consequences information was likely provided. Participants also received general encouragement to take up the offer of the vaccination and were told how to go about accessing the vaccine.

The Daltroy et al., (2007) study provided one of the more in depth intervention descriptions making it easier to confidently determine which behaviour change techniques had been employed. General information about the link between recommended behaviours and health as well as behaviour consequences was provided. Barriers to behaviours were identified and solutions given and participants received instruction about how to correctly and effectively perform behaviours such as tick removal as well as demonstrations of the behaviour. In addition, participants were able to practice the behaviours themselves and were given feedback about their attempts and the opportunity for social comparison. Finally, participants were also provided with various cues to help them determine when to engage in the recommended behaviours.

Malouin et al., (2003) also provided slightly more detailed information about the study interventions making it clear that participants were given relevant health education materials that highlighted recommended behaviours. Barriers to behaviour uptake were identified and mitigated and instruction was given about how participants were expected to perform behaviours. Participants filled in regular reports to self monitor their behaviour and were provided with prompts and cues to help them increase behaviour uptake.

Discussion

Current evidence

Improving the uptake of protective behaviours among members of the public is an important challenge for those working to reduce the incidence of tick-borne disease. It is therefore remarkable that so few good quality studies have assessed the effectiveness of educational interventions in improving this uptake. I identified only nine such studies in my systematic review, of which only three took the form of a randomised controlled trial (Lawless et al., 1997; Malouin et al., 2003; Daltroy et al., 2007). Although I cannot be certain that I included every relevant study in my review, the nature of publication bias makes it unlikely that I missed any well-designed studies which described a successful intervention. As such, the level of

research in this field is disappointing. The success of health education campaigns is never guaranteed. Sometimes, even the most well-planned of campaigns can give poor value for money, while in the worst case scenario they may even back-fire by reducing performance of the very behaviours that they were meant to endorse. Indeed, at least one intervention described in the tick literature appears to have resulted in precisely this type of effect, being associated with reduced knowledge about tick-borne disease and decreased perceptions about the likelihood of personally contracting it (Gould et al., 2008). Greater emphasis on evaluating health promotion material relating to tick-borne disease is clearly required.

Yet despite the paucity of evidence, I did find suggestions that educational material can be effective. In terms of behaviour, the interventions that have been tested to date have noted shifts in uptake of a range of personal protective measures, including the use of insecticide (Lawless et al., 1997; Malouin et al., 2003; Daltroy et al., 2007), better checking for ticks (Lawless et al., 1997; Malouin et al., 2003; Daltroy et al., 2007) and avoidance of areas where one might encounter ticks (Lawless et al., 1997; Daltroy et al., 2007). Changes have also been observed in a range of variables relating to knowledge of and attitudes towards ticks, tick-borne disease and protective behaviours. For example, changes have been noted in perceptions about the likelihood of contracting Lyme disease (Gould et al., 2008), the risks and benefits of tick repellent use (Malouin et al., 2003) and confidence in one's ability to perform tick checks (Maher et al., 2004), together with basic knowledge about ticks, tick-borne disease and protective behaviours (Lawless et al., 1997; Nolan & Mauer, 2006; Malouin et al., 2003; Jenks & Trapasso, 2005; Gray et al., 1998; Maher et al., 2004; Gould et al., 2008; Fox, 2008). Given that such perceptions may serve as precursors for behaviour changes (Abraham & Sheeran, 2005) the finding that these variables are amenable to change via the use of health promotion material in this field is encouraging.

Predictors of tick protective behaviour

An important factor to consider when developing new interventions regarding ticks and tick-borne disease is an understanding of what predicts tick protective behaviours in the real world. Existing studies have tended to target intervention materials towards variables that the researchers and topic experts suspect are potential predictors of tick protective behaviours rather than predictors that have been identified through observational research with specific study populations (Gould et al., 2008; Jenks & Trapasso, 2005). However, observational studies could help to identify behavioural predictor variables and are therefore worth reviewing.

Several studies have assessed whether perceived likelihood of either being bitten by a tick or developing Lyme disease predicts engagement in protective behaviours. Beaujean, Bults, van Steenbergen and Voeten (2013) used an online survey of 362 members of the Dutch general public to identify perceptions and predictors of tick protective behaviour. The behaviours which participants were asked to report on were wearing protective clothing (long sleeves/trousers), using a repellent, checking for ticks and removal of ticks. Among this population perceived likelihood was reported as an important predictor of wearing tick protective clothing, using a repellent and performing a tick check. Brown, Cartter, Hadler and Hooper (1992) reported similar results in a telephone survey of 200 Connecticut households, which asked people to report whether they checked for ticks, removed ticks from pets, avoided wooded areas, wore long trousers or used repellents in tick affected areas. They found that participants who perceived their chances of acquiring Lyme disease in the coming year to be high were more likely to have reported taking precautions against ticks in the past year. In a computer assisted telephone survey of 4246 members of the general public in Connecticut, Maine and Montana (high, low and zero tick incidence locations) Herrington et al. (1997) found virtually identical results when asking participants to report engagement with tick protective behaviours. These behaviours were wearing long trousers, performing a tick check, using a repellent and avoiding wooded areas. A later study by Herrington (2004), which used a random-digit-dial method to collect cross-sectional data from every US state, plus the District of Columbia, asked participants to report on the same behaviours and also found perceived likelihood to be a predictor of reported protective behaviour uptake.

The evidence relating to the perceived severity of Lyme disease is less clear. The study by Beaujean et al., (2013) also indicated that perceived severity of Lyme disease may predict the uptake of tick checking, use of repellent and wearing of protective clothing. The RCT by Daltroy et al., (2007) described earlier in this chapter also found perceived severity of Lyme disease to be a predictor of engagement in tick protective behaviours. However, two studies have found no association between perceived severity and the uptake of tick protective behaviours. The first of these was a survey of a total of 178 visitors to three tick endemic recreational parks in New Jersey in a study by Hallman et al., (1995). The survey was conducted during a time of year when ticks are active. The behaviours assessed in this study were wearing long, light coloured clothing (shirt and trousers), tucking trousers into socks, wearing a hat, wearing closed shoes, avoiding long grass/staying on trails, using a repellent and checking self and/or others for ticks. Behaviour was assessed both through survey questions and through observation by the researchers. For example, researchers were able to observe

whether someone was wearing long trousers, but relied on the participant to tell them whether this was in an attempt to avoid tick bites. The second study which did not find perceived severity to be a behavioural predictor was a cross-sectional survey by Heller et al., (2010) assessing behaviour and attitudes towards Lyme disease among a Brazilian population in Martha's Vineyard, Massachusetts. A total of 103 participants were surveyed and were asked to report whether they limited time spent in tick affected areas, whether they checked themselves or their children for ticks, and whether they used a repellent or long trousers to avoid ticks. Those participants who reported engaging in these behaviours were not significantly more likely to be concerned about the health risk posed by Lyme disease.

Past experience with ticks or Lyme disease, or knowing someone with such experience, predicted uptake of protective behaviours in two of the studies already discussed (Brown et al., 1992; Herrington et al., 1997). This was also identified as a significant predictor in a study by McKenna, Faustini, Nowakowski and Wormser (2004) during which 219 people attending a Lyme Disease Diagnostic Center in New York State completed a questionnaire about their tick prevention behaviour. While all participants had some experience of ticks or Lyme disease, those who reported having had Lyme disease in the past were significantly more likely to use protective behaviours. Contrary to these findings, Hallman et al., (1995) found no association between past experience and behaviour uptake. A study by Phillips et al., (2001) involving a postal questionnaire sent to all residents of Nantucket Island, Massachusetts asked a total of 4671 participants to report whether they wore protective clothing, used a repellent, avoided tick areas or performed a tick check and also failed to find any significant association between experience and reported uptake of tick protective behaviour.

Several studies have shown that a greater knowledge about ticks and Lyme disease predicts more engagement with protective behaviours (Beaujean et al., 2013; Brown et al., 1992; Herrington et al., 1997), with only one study reporting that an increased general knowledge of ticks did not predict behaviour change (Daltroy et al., 2007). Both response efficacy and self efficacy were also identified as predictors of behaviour by Beaujean et al., (2013) and Daltroy et al., (2007). A postal questionnaire study conducted by de Vries and van Dillen (2002) with 230 parents in the Netherlands found that self efficacy was a predictor of tick checking behaviour among parents.

Additional predictors of tick protective behaviour in these observational studies were older age (McKenna et al., 2004; Phillips et al., 2001), being unemployed or retired (Beaujean et al., 2013) and perceiving the behaviour to be a responsible action (Beaujean et al., 2013).

I would suggest that the discrepancies in predictor variables highlighted above are a result of differences in terms of study populations and measurement methods as illustrated in table 1.3. For instance, research by de Vries and van Dillen (2002) determined that predictors of parents performing tick checking behaviour on their children included anticipated regret and the modelling behaviour of other parents. These predictors are likely to be unique to this population and help to highlight the importance of determining the behavioural predictors for a target population prior to designing or disseminating communication materials. The study by McKenna et al. (2004) is another example of research where the identified behavioural predictors are likely to be specific to the study population as all participants had some level of experience with ticks or Lyme disease. Furthermore, the majority of studies did not identify the predictors of each individual tick protective behaviour. Instead, all protective behaviours tended to be grouped together which means it is difficult to determine whether a predictor is specific to one behaviour or whether it might be applicable to all tick protective behaviours. Of the 10 observational studies discussed above, it was notable that 7 of them used a composite measure of protective behaviour, rather than attempting to identify predictors of the individual behaviours. It seems unlikely, however, that each of these behaviours would have the same predictors: a person's willingness to use tick repellent is likely to be affected by different psychological variables than their willingness to tuck their trousers into their socks, for example.

These issues notwithstanding, current evidence from observational studies suggests that RCTs that focus on perceived likelihood, perceived severity and increasing self and response efficacy may have the greatest chances of affecting behaviour.

Table 1.3 Studies identifying predictors of tick protective behaviours

Reference	Design, sample and country	Behaviours assessed	Predictors of behaviours – not broken down to predictors of specific behaviours unless specified (effect size given where known)
Beaujean, 2013	Cross-sectional. Internet survey of 550 members of the general public. Netherlands.	Wearing protective clothing; tick checking of skin after being outdoors; using insect repellent on skin	Wearing protective clothing predicted by: being unemployed/retired (OR 1.96; 95% CI 1.24-3.08); higher levels of knowledge (OR 1.69; 95% CI 1.07-2.68); higher levels of concern about LD (OR 2.22; 95%CI 1.41-3.51); higher levels of perceived efficacy of wearing protective clothing (OR 2.97; 95% CI 1.17-7.54) Checking the skin for ticks predicted by: experienced tick bites in the past (OR 2.19; 95% CI 1.27-3.78); higher knowledge levels (OR 2.83; 95% CI 1.74-4.58); higher levels of concern about LD (OR 2.83; 95% CI 1.71-4.60)
Brown, 1992	Cross-sectional. Telephone survey of 200 households. US.	Looking for and removing ticks after visiting a wooded or grassy area; wearing long trousers; removing ticks from pets; avoiding wooded areas; using insect repellent on skin	Predictors of behaviours: knowing 'a lot' about LD ($p<0.001$); perceived chance of acquiring LD in coming year as high ($p=0.02$); knowing someone with LD ($r=1.5$; 95% CI 1.1-2.1)
de Vries, 2002	Cross-sectional. Postal survey of 230 parents. Netherlands.	Parents performing a tick check of their child/children.	Parental performance of tick check predicted by: moral norms, emotional attitude, anticipated regret, role models, stress self-efficacy
Hallman, 1995	Cross-sectional. In-person survey of 178 visitors to 3 recreational parks. US.	Wearing light coloured clothing; wearing long trousers/sleeves; tucking trousers into socks; wearing closed-toe shoes; staying on trails; avoiding long grass, woods or brush; using repellents; checking body for ticks	Predictors of behaviours: perception that LD is difficult to cure ($r(177)=0.16$, $p<0.02$); perception that someone respondent knew who was bitten was bitten in a place near respondent's home, or where respondent goes ($r(121)=0.216$, $p<0.002$)
Heller, 2010	Cross-sectional. In-person surveys with 103 Brazilian immigrants. US.	Limiting time spent in tick areas; checking self or child for ticks after walking or working outdoors; wearing long trousers; using insect repellent	Predictors of behaviours: being an outdoor worker ($p=0.04$); higher confidence (self-efficacy) in ability to recognize LD symptoms ($p=0.01$)
Herrington, 1997	Cross-sectional (pilot study). Telephone survey of 4246 members of the general public in Connecticut, Maine and Montana. US.	Wearing long trousers in woods/grassy areas; checking for and removing ticks after visiting wooded/grassy area; using insect repellent on skin or clothes; avoiding wooded areas	Predictors of 'having taken specific steps in the past year to prevent oneself from getting Lyme disease': perceived risk of getting LD (Connecticut OR=1.9; Maine OR=2.6; Montana OR=2.0); moderate to high levels of knowledge about LD (Connecticut OR=1.6; Maine OR=1.7); knowing anyone with LD (Connecticut OR=2.1); age from 18 through 44 years (Montana OR=2.0); being married (Connecticut OR=1.7); use of a repellent (Maine OR=1.7)

Herrington, 2004	Cross-sectional. Telephone survey of 1750 members of the public. US.	Using insect repellent on skin or clothes; wearing long sleeves and trousers; tucking socks into trousers; avoiding woods and grassy areas	<p>Predictors of behaviours in high endemic areas: knowing someone with LD (OR=4.1; 95% CI 1.3-12.6); knowing how someone gets LD (OR=22.1; 95% CI 3.6-136.5); concern about being bitten (OR=4.4; 95% CI 1.3-15.3); high perceived severity of LD (OR=0.1; 95% CI 0.02-0.5)</p> <p>Predictors of behaviours in low endemic areas: high perceived severity of LD (OR=2.6; 95% CI 1.1-5.7); concern about being bitten (OR=11.2; 95% CI 5.8-21.8); regular newspaper reading (OR=2.07; 95% CI 1.04-4.13); pet ownership (OR=2.19; 95% CI 1.12-4.29); being unmarried (OR=0.45; 95% CI 0.23-0.90)</p>
McKenna, 2004	Cross-sectional. Survey completed by 219 people attending an LD clinic. US.	28 items including habitat control strategies and all usual personal protection behaviours	Predictors of behaviours: having a history of LD (OR=2.55; 95% CI 1.21-5.37); family member or close friend with LD (OR=1.95; 95% CI 1.13-3.37)
Phillips, 2001	Cross-sectional. Postal survey of 4671 residents of a Lyme endemic area. US.	Avoiding tick areas; checking oneself for ticks; wearing long trousers and sleeves; using insect repellent	<p>Predictors of avoiding tick areas: being female (p=0.001); older age (p=0.001)</p> <p>Predictors of checking oneself for ticks: being female (p=0.001)</p> <p>Predictors of using insect repellent: being female (p=0.001); older age (p=0.001)</p> <p>Predictors of wearing long trousers and sleeves: older age (p=0.001)</p>

LD = Lyme disease

Suggestions for future research

Plenty of scope exists for future work to expand this literature and advance our knowledge of how best to encourage members of the public to take protective action when exposed to the risk of tick-borne disease. Future studies could be improved by learning several methodological lessons from those studies which have already been completed.

First, randomised controlled trials are still largely absent in this area, with only three notable exceptions. The use of before and after studies, or self-allocation to experimental groups, makes it difficult to determine whether any behavioural changes that are observed have happened due to any pre-existing differences between participant groups, due to the passage of time, or because of a genuine effect of the intervention. While before and after studies, together with cross-sectional surveys or qualitative research, may be useful for pilot studies, full studies on the efficacy or effectiveness of an intervention should make use of the best quality experimental designs, with their final reports following well-defined best practice (www.consort-statement.org) (Evans, 2003). Despite their relative expense in comparison with other study designs, randomised controlled trials provide the most accurate assessment of the efficacy of a given intervention and usually represent value for money.

Second, the majority of the studies conducted to date have relied on self report to measure behaviour. This poses limitations. Self-report may reflect actual behaviour, but can also be influenced by numerous other factors, including the social desirability of reporting 'good' behaviour, recall bias, and systematic changes in a participant's understanding of what counts as effective behaviour. To take one example, while Fox (2009) reported a trend for reduced self reported checking for ticks by children following her educational intervention, it is unclear if this is because the behaviour changed or if the intervention changed participant's perceptions as to what a check for ticks actually is. While obtaining objective measures of behaviour is difficult, attempts should be made to at least validate any self-report measures that are used. Ensuring that questions about behaviour accurately reflect the changes that may be brought about by an intervention is also important. It is possible that some tick protective behaviours may also be practiced for reasons other than tick avoidance, for example, wearing trousers because of colder weather. Unless questions specifically refer to practicing behaviours for tick avoidance then it is possible that results may be inaccurate in assessing the efficacy of an intervention.

Third, two studies (Jenks & Trapasso, 2005; Gray et al., 1998) did not assess behaviour at all, but instead focused solely on measures of knowledge. While increased knowledge may lead to behaviour change, improved knowledge by itself is a poor proxy for improved protective behaviour. For example, a study at three recreational parks in New Jersey found that 84% of participants were able to name at least one precautionary behaviour against tick bites, but despite this only about half actually engaged in any of the behaviours (Hallman et al., 1995).

Fourth, studies involving different sample populations have shown the importance of designing and evaluating interventions with multiple audiences in mind. Different populations will differ in terms of both their pre-existing level of knowledge and perceptions about tick-borne disease and their risk of contracting a disease. The same intervention may have different effects depending on who it is tested on (e.g. Daltroy et al., 2007) and may need to be adjusted depending on which population is the target. Immigrant populations to Lyme endemic areas have little if any knowledge of tick-borne disease, but this can be raised through targeted interventions (Heller et al., 2010, Jenks & Trapasso, 2005). Visitors to tick endemic areas also show a similar lack of knowledge but may require more specific interventions (Shadick et al., 1997). Perhaps most challenging from a health education perspective may be those living in tick affected areas, who may already have their own idiosyncratic views of the risks associated with ticks and how best to reduce them, views which will not always correspond to those held by health experts but which might prove difficult to change. Knowledge of tick-borne disease among health professionals should also not be overlooked, as this has been shown to be low, even in endemic areas. This is true of both Lyme disease in North America (Capps, Pinger, Russell, & Wood, 1999) and CCHF in Eastern Europe (Rahnavardi et al., 2008). Surprisingly, 22% of Turkish healthcare workers fail to take any precautionary measures when in contact with CCHF patients despite the contagious nature of the disease (Rahnavardi et al., 2008). To date, research into the effectiveness of intervention materials has focused on Lyme disease, but the fundamentals of effective communication strategies that they highlight might be applied to any tick-borne disease, assuming that other appropriate intervention options, such as land management, have been taken into account (Quine et al., 2011).

Fifth, the follow up period used by studies in our review varied. A relatively lengthy follow-up is important, as at least one study has demonstrated that significant changes identified one month after the intervention had greatly reduced 6 months later (Lawless et al., 1997). While triggering behaviour change may be possible, maintaining it in the long-term is likely to prove more difficult. Related to this, the timing of any follow up should also correspond to the local

tick season. Behaviour is not expected to differ from normal outside of the tick season, so any follow up conducted outside of the season may not detect any changes (Malouin et al., 2003). Where interventions are applied at a population-level, surveillance systems may provide one option for long-term follow-up.

Sixth, the explicit use of psychological theory to inform intervention development has been limited in this literature, again with a few notable exceptions (Daltroy et al., 2001; Maher et al., 2004; Jenks & Trapasso, 2005). Theories such as the health belief model, the theory of planned behaviour and others have shown much success in helping to improve the uptake of protective behaviours across a wide range of health topics, from condom use to smoking cessation to exercise (Armitage & Conner, 2000). Designing an intervention on the basis of qualitative interviews with the target population and a consideration of the mechanisms for behaviour change suggested by these theories is likely to give the best chance of success as demonstrated by the studies in this review. For example, the study by Daltroy et al., (2001), which described the inclusion of psychological theory as guidance for the development of interventions, produced more in depth and targeted interventions which resulted in changes to behaviour in addition to knowledge and awareness.

Seventh, the quality of reporting in this field regarding the exact interventions that were used is poor. Several studies failed to provide sufficient detail for a reader to understand the nature of their intervention or how to replicate it, and while it is possible that some studies which did not mention using any theoretical model to guide their interventions were indeed informed by a theory of behaviour change, I was unable to determine this from the information provided. Without details about the nature of interventions and the processes driving their design it is difficult to interpret the results (Michie, Fixsen, Grimshaw, & Eccles, 2009).

Finally, those randomised controlled studies that do exist have been well designed, but have tended to focus on a complex combination of both interventions and outcome variables. Multi-modal interventions involving the use of reminder cards, entertainers, free samples of repellent, leaflets, maps of tick hot-spots and other materials may be effective, but are clearly labour intensive and costly (Malouin et al., 2003; Daltroy, 2007). There may be some aspects of these multi-modal interventions which are more effective than others. Identifying them might allow for a more focused and efficient intervention. Additional research to determine which type of material is most effective at eliciting the desired behavioural changes would be of use. This could be conducted in the form of component studies which help to identify the

feasibility, acceptability and likely effectiveness of the individual parts of a larger intervention (Simon et al., 2001).

Improving future research – a role for behaviour change theory?

It is possible that the behaviour change techniques identified above for each study are not an exhaustive list of all those that were included. Given the mixed and generally not very detailed nature of the intervention descriptions in these studies it is difficult to be completely confident about the use of particular techniques. This gives credence to the argument put forward by Abraham & Michie (2008) that there is a real need for a standardised vocabulary for intervention reporting. If study authors had a standardised list of behaviour change techniques to guide their intervention write up then it would aid understanding of the interventions and improve replicability, but would also encourage researchers to take the techniques into consideration when planning and designing the intervention.

Improving future research – a role for disgust?

Although traditional behaviour change models propose a range of variables which might be targeted in a future intervention, additional triggers for behaviour change exist which may also be worth exploring. One particularly important driver of tick protective behaviours may be the emotion of disgust. To the best of my knowledge there are currently no studies looking at whether the uptake of tick protective behaviours can be effectively increased through the use of disgust-based messages.

Existing theories of behaviour change are closely linked to theories investigating fear appeals, which attempt to alter individual's intentions and to motivate them to increase the uptake of health protective behaviours. Fear has long been recognized as a motivator for avoidance of perceived dangers and a number of theories have been developed and studied to explain the role that fear can play in behaviour change. Protection Motivation Theory (PMT) is organized into two separate processes of threat appraisal and coping appraisal (Floyd, Prentice-Dunn, & Rogers, 2000). A threat appraisal is formed by an individual based on their perceived likelihood of a particular event occurring and their perceived severity of the event (Rogers, 1975). The way in which an individual chooses to respond to a threatening situation is termed the coping appraisal and is based on both the belief that uptake of recommended behaviour will resolve the threat (response efficacy) and an individual's belief in their own ability to effectively perform the behaviour (self efficacy) (Cameron, 2009). The Health Belief Model (HBM) encompasses many of these aspects, but does not attempt to make any links between

the cognitive processes involved in threat appraisal and coping appraisal. In addition to PMT, the other main theory based on fear appeals is the Extended Parallel Process Model (EPPM) which expanded from the earlier Parallel Process Model (PPM). EPPM is comprised of two particular appraisals, both of which are nearly identical to those in PMT. The first of these is the threat appraisal where one assesses the perceived susceptibility to and severity of a threat (Cameron, 2009). Assuming that these two perceptions are high, the individual then moves on to make an efficacy appraisal which incorporates both the response efficacy and self efficacy as discussed in the PMT (Cameron, 2009). Although PMT and EPPM are very similar, the main differentiating factor is that while PMT posits that individuals will engage in behaviours that are most rewarding or which are punishment avoiding, EPPM incorporates an emotional response as well as this cognitive response (Cameron, 2009). Use of both of these fear appeals models has been widespread and has covered a wide range of health interventions and behaviours including cancer screenings, HIV/AIDS prevention and promotion of bicycle safety helmets (Floyd et al., 2000; Witte, 1994; Witte, Stokols, Ituarte, & Schneider, 1993). Despite this widespread usage neither model has become a clear favourite within the domain of fear appeal studies. Clearly many theories exist to try and understand and elicit behaviour changes, but all highlight aspects of response efficacy or self efficacy, severity and likelihood.

A relatively new addition to the field of behaviour change research is the so-called 'behavioural immune system'. The physical immune system is a bodily defence to protect against harmful parasites, but it is only able to defend against infectious agents once they have already come into contact with the body (Schaller & Duncan, 2007). The behavioural immune system is therefore proposed as another line of defence, but one which has evolved to keep people from coming into contact with infectious agents to begin with through the ability to detect the potential presence of parasites in people and things around oneself and to engage in protective behaviours to avoid contact with these potential sources of infection (Schaller & Duncan, 2007). A key component of the behavioural immune system is the emotional state of disgust which acts as a motivator for the behavioural avoidance of a wide variety of potentially infectious agents (Schaller & Park, 2011).

Although disgust and fear were both included among a list of six basic emotions argued for by Darwin (1872), until recently they have often been regarded as one and the same emotion when it comes to motivators for behavioural change. Initially seen as a food-related emotion, disgust has been proposed to be an adaptive evolutionary strategy to reduce the likelihood of infection (Phillips, Senior, Fahy, & David, 1998). While disgust and fear may appear similar,

there are in fact a number of differentiating factors. Disgust is characterised by a particular facial expression which typically involves a wrinkling up of the nose and lowering of the corners of the mouth; specific neurological signs including lowered blood pressure, lowered galvanic skin response and nausea; and also by a series of potential actions such as stopping, dropping and shuddering (Curtis & Biran, 2001). In contrast, fear elicits a different facial expression and a heightened neurological response in preparation for the classic fight or flight response rather than the suspension of activity which is seen with disgust (Curtis & Biran, 2001). MRI studies have suggested that a particular region of the neurological substrate within the anterior insular cortex is involved in the perception of disgust, further separating it from fear, though this needs to be confirmed through more studies (Phillips et al., 1997). A final defining characteristic of disgust is that it has also evolved to include a cultural component elicited by immorality and the violation of particular social rules, for example, incest (Curtis & Biran, 2001). There is clearly an intersection or overlap between the emotions of disgust and fear given that they both represent defensive responses and provide a protective disease avoidance function, however fear motivated avoidance protects from a perceived danger while disgust motivated avoidance is linked more to a specific sensation or image related to contamination (Woody & Teachman, 2000).

Few studies have tested the role of disgust as a behavioural motivator and to the best of my knowledge there is only one study that has investigated the role of disgust as a motivator for the uptake of tick protective behaviour. Research by Hallman et al. (1995) asked participants about perceptions of disgust towards ticks as they hypothesized that level of disgust could have an impact on the uptake of protective behaviours, but no significant association was found. This result is interesting; however it would be beneficial to use a more robust set of disgust measurements and to determine whether disgust-based messaging might have a role to play in behaviour uptake. Research which has focused on disgust motivated behaviour change has tended to look at issues of hygiene, particularly the behaviour of hand-washing. Until recently the promotion of health behaviours has been based on campaigns to increase knowledge. Although such campaigns have been moderately successful (Loevinsohn, 1990), the incorporation of disgust messages has shown greater success (Botta, Dunker, Fenson-Hood, Maltarich, & McDonald, 2008). A study in Ghana investigated the effectiveness of a variety of communication channels in promoting the uptake of hand-washing with soap (Scott, Schmidt, Aunger, Garbrah-Aidoo, & Animashaun, 2008). Communication channels included television, radio, community events, posters and billboards and all messages were targeted at mothers of children aged five years or younger. Instead of an educational message about

germs, investigators designed messages aimed to evoke feelings of disgust and a desire for cleanliness. This was achieved by using the desire to avoid contamination and the desire to respond to social norms as behavioural drivers. Results from the comparison of pre and post campaign surveys showed a significant increase in hand-washing with those who had attended a community event and heard the message on at least one mass media channel showing the greatest effect. These results indicate that disgust can be a powerful driver of behavioural change, but because there was no control message it is not possible to determine whether other messages would be more effective.

A recent study based in England used wireless sensors in the public restrooms of a highway service station to detect and record the number of people entering and leaving each restroom as well as each soap use (Judah et al., 2009). A variety of different intervention messages were presented in the restrooms over the course of the study, all aiming to increase the number of people who washed their hands with soap. Each message contained the word “soap” and was based on one of seven different domains of behaviour change theory of which disgust was one. Interestingly, the results showed significant differences between men and women. For men, disgust messages led to a significant increase in the use of soap, while for women disgust messages were only slightly better than the control condition. Messages that aimed to increase knowledge about hand-washing were the least effective messages among males; however they led to significant increases among female participants. Such a divide between men and women could have important implications for the effectiveness of campaigns for health behaviour change. Importantly, there is evidence to suggest that simply providing information in an attempt to increase knowledge is not enough to motivate behaviour change in men; however it does seem to work for women (Judah et al., 2009). Further studies could help to clarify whether this gender difference in disgust motivation is specific to particular health behaviours or whether it can be applied more generally.

Although I was not aware of any research into disgust as a motivator for the uptake of tick protective behaviour, a study aiming to understand the association that exists between disgust and macroparasites included ticks as one of their stimuli (Prokop & Fancovicova, 2010). The researchers wanted to determine if all invertebrates were perceived with an emotion of disgust, or whether behaviours linked to disgust or fear might be specific to invertebrates which pose a risk of parasitic infection. Participants were shown 25 different invertebrates, of which some were controls, and rated them for fear, disgust and perceived danger. Each participant also completed a questionnaire asking them about various risky behaviours

associated with transmission, such as avoidance of animals. Participants with higher scores performed these behaviours more frequently. The 25 invertebrate pictures were broken into five categories and the ectoparasites, of which ticks were one, rated significantly higher than the others on fear, danger and disgust, particularly among female participants. Those participants who had higher ratings of disgust tended to practice behaviours such as avoidance of animals and washing their hands more frequently than those with lower ratings. This evidence that ticks do elicit a feeling of disgust, coupled with the evidence that disgust can motivate behaviour change, suggests that a disgust-based intervention to increase the uptake of tick protective behaviours is well worth trialling as there are indications that it could be effective.

Improving future research – thesis aims

In addition to the review of existing literature as detailed in this chapter, the research described in this thesis had five specific aims:

- To identify levels of knowledge and perceptions of tick-borne disease in the UK
- To identify drivers of and barriers to tick protective behaviour
- To determine which factors are most strongly associated with the uptake of protective behaviours
- To design and pilot test the effectiveness of communication materials at increasing the uptake of protective behaviours
- To determine the sample size for a full randomised controlled trial

CHAPTER 2: QUALITATIVE INTERVIEWS

Introduction

The overarching aim of this project was to find an effective way of encouraging members of the public to protect themselves against tick bites. As discussed in chapter 1 the existing research literature is scant, particularly in the UK. Although the tick literature does provide details about prevention strategies, there is little information available regarding the drivers behind these behaviours. Information that does exist tends to have an American focus and is not necessarily generalisable to the UK population and context. As a starting point for data collection I decided that it would be useful to run a series of qualitative interviews in order to make explicit the current state of affairs in the UK regarding tick prevention behaviours, factors that motivate people to engage in them and potential barriers to their widespread uptake.

A mental models approach was chosen as the most suitable method of organising the data because it meshes well with theories of health psychology by mapping out the pathway between exposure and disease.

Jones, Ross, Lynam, Perez and Leitch (2011) provide a clear description of mental models:

Mental models are personal, internal representations of external reality that people use to interact with the world around them. They are constructed by individuals based on their unique life experiences, perceptions, and understandings of the world. Mental models are used to reason and make decisions and can be the basis of individual behaviours. They provide the mechanism through which new information is filtered and stored.

Each of us constructs mental models as a way to understand different aspects of the world around us. These models, which are usually expressed by researchers as a flow diagram, play a role in decision making and in this project they are a particularly useful way of making explicit all of the factors that influence behavioural change regarding tick-borne disease. Physically mapping out a mental model provides a useful representation of the thought processes that drive behaviours, although they tend to be incomplete representations of reality as they are unique to each individual and are continually changing due to their dependency on context (Jones et al., 2011). Because of this personal aspect, mental models can help to highlight knowledge gaps and misunderstandings where future communication or interventions could potentially be focused.

Mental models also work well in combination with theories of health psychology as they can help to draw out information on which behaviours people engage in, barriers or benefits of these behaviours and the drivers for particular behaviours. Although initially focused on the individual, mental models research has expanded to incorporate a collective aspect, recognising that even at an individual level there is a social component to cognition and decision making (Jones et al., 2011).

Conventionally, the mental models approach to developing communication materials has involved both expert interviews in order to understand the problem at hand, followed by lay interviews to see how members of the public view the problem. The same approach was adopted for this study.

Initially interviews were conducted with 13 topic experts. These interviews were designed to identify the protective behaviours that the general public could engage in to most effectively avoid ticks and tick-borne disease. They were also useful in generating qualitative data suggesting some potentially important behavioural drivers in the primary and secondary prevention of tick-borne disease in the United Kingdom.

The behaviours identified in the interviews with topic experts became the basis of the next round of interviews, this time with 25 members of the public who lived in London and were members of an outdoor walking or rambling organisation. The participants were chosen so as to obtain a sample of members of the public who live in an urban environment, but who are at risk of tick bites through their leisure activity. This group of people are of particular interest because they may not be as regularly exposed to information about tick or Lyme disease as people who live in tick-endemic areas, but are nonetheless likely to come into contact with ticks due to their leisure pursuits. Having determined the recommended behaviours by speaking with topic experts, the public interviews provided an opportunity to examine the factors that influence whether or not people engage in each of these behaviours.

Expert Interviews

Methods

Design

A round of in-depth, one-to-one interviews was held with topic experts. All interviews were conducted between February and April 2011 and took place either at the Denmark Hill Campus of King's College London, at the professional office of the participant, or in the case of two participants, over the telephone.

Participants

The participants were chosen so as to obtain a small, but varied sample of UK tick experts. Colleagues from the Medical Entomology and Zoonoses Ecology team at the Health Protection Agency provided a list of professional contacts in the United Kingdom who specialise in an aspect of tick expertise. Of these 17 contacts who were invited to take part in the interviews, 13 professionals agreed to be involved. Interviews were conducted with experts from the following broad range of tick-related professions: clinical epidemiology (n=1), parasitology (n=1), psychiatry (n=1), tick surveillance (n=1), wildlife and land management (n=2), medical entomology (n=3), and university based professors or researchers specializing in ticks (n=4). Participants were deliberately sampled from a variety of different professions in order to ensure that there was a broad overview of the topic.

Interview schedule

An interview schedule was developed to cover four topics relating to ticks and tick-borne disease. Firstly, experts were asked about how a tick can end up on a human. This involved such discussion topics as what risk is posed by ticks, how people come into contact with ticks and the possible tick control methods and protective behaviours that one could adopt. Secondly, there were questions about how someone can contract Lyme disease. These ranged from what to do if bitten by a tick to appropriate and inappropriate removal strategies. Thirdly, experts were asked more specific questions about the nature of Lyme disease such as how severe it can be, difficulties regarding treatment and the symptoms. Finally, there were also questions about public health communication and disgust as they relate to ticks and tick-borne disease. Experts were asked about things such as any perceived potential barriers to practicing tick protective behaviours and any particular messages that they felt the public needed to hear regarding ticks and tick-borne disease. The full version of the topic expert

interview schedule can be seen in appendix 3. The interview schedule acted as a guide to ensure that particular topics were covered, but topics could be discussed in any order and the interviewer used the schedule as a prompt.

Procedure

Each participant was first contacted by email to establish interest in the project and to set up a suitable interview time. Those who agreed to participate were asked to arrange a suitable time for their interview. Each interview was approximately 45 to 60 minutes in length. The interviews were audio recorded and were later transcribed by the researcher. In line with the King's College London ethics approval procedures (ethics approval code: PNM/10/11-19) the anonymity of each participant was maintained. Participants were provided with consent forms describing their right to withdraw from the study and the contact details of the researchers if they had any further questions after they had participated in the interview.

Analysis

The transcripts were analysed using qualitative methods. Qualitative research aims to understand, communicate and represent the experiences and actions of individuals as they encounter them in everyday life. A variety of different analytic methods exist for dealing with qualitative data, but it is not the aim to verify earlier conclusions or theories, only to provide greater insight into the topic of study (Elliot, Fischer, & Rennie, 1999).

A style of qualitative analysis known as thematic analysis was used to analyse the data. Thematic analysis is a way of identifying, analysing and reporting data patterns, otherwise called themes. Following transcription the data was first coded as a way of organising the data. Coding is a process whereby the data is classified into different categories to make sense of the information and to facilitate analysis (Taylor & Gibbs, 2010). All coding was done using NVivo software. Rather than developing a coding frame prior to beginning the analysis, the codes emerged as the analysis was undertaken. When all of the data had been coded a second stage of analysis was conducted to develop these codes into themes. Some codes were considered to be themes themselves, such as awareness relating to tick-borne illness. Other codes such as incorrect removal and speed of removal were grouped together into one common theme focused on all aspects of removal. Themes capture the important parts of the data in relation to the research questions, but level of importance is not necessarily related to how often it appears (Braun & Clarke, 2006). Because this project was about getting people to engage in tick protective behaviours, particular interest was paid to codes that were relevant

to behaviours. Once identified, the codes were worked into a mental model to represent the understanding of tick-borne disease and the potential drivers and barriers behind key prevention behaviours.

Results

Participants described multiple possible ways of reducing the risk of tick-borne disease. The focus of these strategies often reflected the disciplinary focus of the participant. For example, controlling deer populations and maintaining biodiversity were described in depth by participants from wildlife and land management professions and the importance of prompt medical attention and treatment by the clinical epidemiologist. Because this study aimed to increase the uptake of tick protective behaviours among members of the UK public, suggested strategies relating solely to land or animal management are not described in detail in this thesis.

The final mental model that arose from interviews with topic experts can be seen in figure 2.1.

The flowchart is divided into two main sections: **Primary prevention (pre-tick bite)** and **Secondary prevention (post-tick bite)**, both leading to **People bitten by ticks**.

Primary prevention (pre-tick bite) pathways:

- Pathway 1:** Knowledge → Light coloured trousers → Tick trousers & socks → Knowledge → Use tick repellent → Apply to clothes → Health, Cost, Time, Hassle, Social norms → Knowledge.
- Pathway 2:** Knowledge → Stick to clear pathways.
- Pathway 3:** Knowledge → Treat pets for ticks.
- Pathway 4:** Experience → Knowledge.
- Pathway 5:** Social norms → Knowledge.
- Pathway 6:** Knowledge → Might make people avoid areas → Knowledge.

Secondary prevention (post-tick bite) pathways:

- Pathway 1:** Tick checks → Aware of bite → Patient's symptom awareness.
- Pathway 2:** Mobility → Tick checks.
- Pathway 3:** Time and hassle → Tick checks.
- Pathway 4:** Correct tick ID → Tick checks.
- Pathway 5:** Knowledge → Removal (Quickly and correctly).
- Pathway 6:** Availability of devices → Removal.
- Pathway 7:** Experience → Removal.
- Pathway 8:** Patient's symptom awareness → Removal.
- Pathway 9:** Patient's symptom awareness → Sometimes non-specific symptoms → Patient's symptom awareness.
- Pathway 10:** Patient's symptom awareness → Prompt medical treatment → Disease severity.
- Pathway 11:** Prompt medical treatment → GP awareness → Training → GP awareness.
- Pathway 12:** Experience → GP awareness.
- Pathway 13:** Experience → Prompt medical treatment.

Legend: Bold text = protective behaviours.

Primary prevention

The mental model that was created based on interviews with topic experts was split into two adjoining sections. The first (see figure 2.1) represents the discussions surrounding primary prevention of tick bites, or the protective behaviours that people can engage in to avoid coming into contact with ticks (e.g. pre-tick bite strategies such as wearing light coloured trousers). There were four main primary prevention strategies that experts discussed. These were tucking long trousers into socks, wearing light coloured trousers, sticking to clear pathways and using tick repellents.

Strategy 1: Wearing long trousers tucked into socks

The first of the tick preventive behaviours which was mentioned was to wear long trousers tucked into socks. This behaviour is recommended as it is meant to limit the ability of the tick to find bare skin where it can attach. Although experts were aware of this prevention strategy there was some reluctance to recommend it, with one expert questioning how effective it might be:

*“People say tuck your trousers into your socks, but I’m not sure because the ticks get caught in your socks so I just prefer long trousers to be honest.”
(Expert 5)*

Even without the uncertainty raised by tick experts, a number of experts felt that important drivers or barriers to performing this behaviour were social norms. Experts themselves reported being unlikely to engage with this behaviour and they felt that the general public would have similar concerns regarding how the behaviour would make them look:

“I don’t think people would follow that advice because I just think, ‘would I follow that...no’. Like tucking your trousers into your socks...nobody does that, I’ve never seen anyone do that because you look stupid.” (Expert 1)

Strategy 2: Wearing light coloured trousers

Rather than tucking trousers into socks, participants felt that a more practical and acceptable behaviour might be to wear light coloured trousers. Because ticks are dark in colour, wearing light trousers makes it easier to spot them, meaning they can be brushed away before they reach bare skin:

“I think that beige trousers down to your ankles are key and regularly checking your legs for ticks on the trousers. If you wear shorts you’re kind of asking for

trouble really because before you know it the ticks are up under your shorts.”
(Expert 5)

Strategy 3: Stick to clear pathways

Another recommendation that was discussed by experts was sticking to clear pathways and avoiding walkways that have overhanging vegetation. Ticks come into contact with a host, including humans, by climbing up the vegetation and waiting for the host to brush against it giving the tick the opportunity to climb aboard. By avoiding this sort of vegetation it makes it unlikely that someone would pick up a tick:

“It’s basically to do with keeping grass mown and making sure that the paths are not within easy reach of surrounding vegetation.” (Expert 6)

“If you walk in the middle of the path and you don’t brush against any overhanging vegetation you won’t get any ticks cause ticks aren’t going to quest and climb up on your feet, but if you go on a path where you have to brush vegetation out of the way then you can guarantee, particularly in woods around here, you’ll get a tick on you.” (Expert 5)

Strategy 4: Use of tick repellents

The final prevention strategy discussed by experts was the use of tick repellents which are available both for pets and for humans. The public are encouraged to apply tick treatments to their pets in order to avoid discomfort for the animal and also to avoid the ticks coming into contact with pet owners. A number of the experts mentioned that although many people may treat their pets for ticks, they may do this simply because they view ticks as a nuisance, but not because they are aware of ticks as a vector of disease:

“I think people treat their pets for fleas and ticks quite regularly, but then I don’t know how aware they are that those ticks are also a risk to themselves.”
(Expert 2)

As well as applying a tick repellent to a pet, experts suggested that repellents can also be used on clothing or skin to avoid tick bites, although considerations such as cost, time and hassle were felt likely to influence usage. There was also felt to be widespread concerns among the public about the health risk surrounding the use of repellents, so it is likely that this could be a barrier for some people:

“I know I don’t use repellents because I wouldn’t want chemicals on my skin every day and I don’t know how effective and safe they are for children. I just think nobody is going to use permethrin every day when they take their dog for a walk...it’s expensive and it doesn’t smell nice.” (Expert 1)

The use of tick repellents was also felt to be influenced by social norms as illustrated by this comment:

“Any responsible dog owner ought to be applying that stuff on a regular basis anyway.” (Expert 4)

Knowledge and experience as key behavioural drivers

As can be seen in figure 2.1, knowledge was believed to be a key driver for each of the prevention strategies outlined in this section. Whether this knowledge actually translates into behavioural change was seen as likely to depend, at least in part, on personal experience. Experience is not something that necessarily precedes knowledge, but is instead something which can influence the extent to which people utilize or act upon the knowledge which they are given. These experiences may include things such as previous exposure to ticks, perhaps occupationally; being affected by Lyme or other tick-borne diseases, or knowing someone who has been; and living in a location where ticks and tick-borne disease are prevalent. A majority of the experts discussed the impact that location has on awareness and experience of ticks, making comments such as:

“I think awareness depends on where you are, I mean if you lived in the New Forest it goes without saying that you would be, but if you’re someone who’s visiting the New Forest from further afield on a holiday...they might not be aware if they’re from an environment where ticks aren’t discussed.” (Expert 8)

Other experts talked about their own experiences with ticks both occupationally and personally:

“I’ve never been bitten and I’ve been working in the field...there are a couple of other members of staff who are probably newer and haven’t had the experience with ticks and they have been bitten and I think that shows if you know a lot about them then you can avoid them, even if you’re in a really high risk area.” (Expert 1)

This comment highlights not only the fact that experience in combination with knowledge can help to increase the uptake of behaviours, but also that these tick protective behaviours, when practiced correctly, are effective at preventing tick bites.

Secondary prevention

Having identified the primary prevention behaviours which help reduce the chances of being bitten by a tick, the second half of the mental model addressed the post-tick bite prevention behaviours (figure 2.1). Three strategies were suggested: performing a tick check, removing ticks quickly and using the correct technique, and seeking medical advice promptly if symptoms develop.

Strategy 1: Performing a tick check

The first stage of secondary prevention as explained by experts is to perform a full body tick check. If a person has been in an area where there might be ticks it is recommended that, as well as following the primary prevention strategies, when they return home they should immediately search their body for ticks. In addition to looking over the body, this also involves feeling difficult to see areas with the hands to catch any ticks that may have attached themselves. One expert explained the importance of performing a tick check:

“As a pathogen, as a disease, it’s 100% preventable. Even if you get bitten by a tick, if you remove it within 48 hours...it’s a big window, I mean 48 hours is a big window to be able to remove it whereas a virus is in less than 15 minutes. So you’ve got a chance of not getting bitten in the first place, then you’ve got a two day window to remove them and then it’s also treatable if you know the symptoms and if you get it early enough with antibiotics.” (Expert 1)

This window of opportunity to remove a tick before the transmission of disease was reiterated by a number of experts, making it clear that this could be a potentially useful area to increase awareness and aim to change behaviour:

“Perhaps the best place to prevent disease is to check yourself...to come in, take a shower, look everywhere because you’ve got this kind of twilight period where the tick is trying to attach and hasn’t begun the big sip, so in theory at least your risk of acquiring infection is lower during that initial period of attachment.” (Expert 3)

The ability to perform a tick check is of course informed by the knowledge that this is something that should be done, but also by the ability to correctly identify a tick:

“I don’t think the public have much perception of ticks; I don’t even know if many of them would know what a tick looked like.” (Expert 7)

Other influencing factors are the potential issues of mobility, time and hassle. A proper tick check needs to be an inspection over all areas of the body including hard-

to-reach and see areas such as behind the knees or around the hairline. One expert suggested that older members of the public may have difficulty performing a full tick check because they may be less agile and flexible, however this could be mitigated with the use of a handheld mirror. Other experts mentioned that people may perceive a tick check as a hassle to perform or as something which takes up a lot of time, but they said that in reality this is not the case:

“I did the head to toe check and it really doesn’t take very long to just run your hands over your skin and just check in a mirror.” (Expert 1)

Ticks checks are also important because they help people to become aware of any tick bites. As mentioned by one expert:

“They won’t necessarily know that they’ve been bitten by a tick, in fact the surveys vary, but a lot of patients, it turns out, were not aware of the tick that bit them.” (Expert 6)

Strategy 2: Tick removal

Tick removal was a topic covered by nearly every expert, with the following main messages emerging. Firstly, the speed of removal was emphasized. Although experts talked about the window of opportunity that exists before the transfer of potential disease, they highlighted the fact that the sooner the tick is found and removed, the better. As well as quick removal, many experts talked about the need for correct, safe removal of ticks:

“I think previously people put Vaseline on them or burnt them off and did all these other things which have now been shown not to be very good because they can actually stimulate the tick to regurgitate and pathogens and saliva will be...it will increase the risk of disease transmission.” (Expert 2)

The ability to quickly and correctly remove a tick was seen as being influenced by experience, with experts suggesting that members of the public who live in tick endemic areas may be better equipped to remove ticks because of their familiarity with them:

“If you speak to people in the New Forest who are...ticks have always been there, they really don’t care about them and they’re not concerned about Lyme at all in the slightest because they know about it, they know what to do about ticks and they don’t freak out and email and phone me and say ‘I don’t know how to remove a tick’, they just know and they can probably remove ticks better than me.” (Expert 1)

In addition to experience, a behavioural barrier mentioned as influencing tick removal was the availability of particular tick removal devices. A number of devices have been designed to ease the process of removing a tick and for those who find tweezers more difficult to use; however these devices are not commonly available in shops and many people are unaware that they exist:

“It’s also interesting that even in a ticky area it’s very difficult to find tick removers. One of the recommendations is remove a tick with fine pointed tweezers or a tick remover and avoiding things like Vaseline and that sort of thing, but on the whole, if you want a tick remover in this country, you don’t go to a pharmacy, you go to the nearest vet clinic. Some people are not very happy about using fine pointed tweezers and they’re much happier using the tick remover, but they’re hard to find.” (Expert 9)

Strategy 3: Patient symptom awareness

Following awareness of a bite and the removal of any ticks, the patient needs to be aware of any possible symptoms of Lyme disease that could occur. Experts suggest that by keeping an eye on a bite site and knowing what symptoms to look for, people will be able to receive treatment more quickly, hopefully reducing the severity of any illness. However, while many Lyme patients exhibit a classic erythema migrans, or bulls eye rash (see figure 2.2 for an example of this rash), not all do:

“You need to keep an eye on your situation, but we now know that a lot of people who are infected don’t actually present, don’t have an erythema migrans at all, so the infection can go straight from the skin into the system.” (Expert 6)

Figure 2.2 Erythema migrans rash



As with the removal process and all of the other preventative behaviours discussed, experience and knowledge play key roles in influencing the awareness of symptoms that could suggest illness. People who have had previous tick bites or know others who have suffered from a tick related illness may be more aware of symptoms themselves and know what they should be vigilant towards. As one expert explained:

“I think to be aware of the rash and what that means and how in children it can present behind the hairline and typical areas where ticks can be found, but I think the rash...if you catch it at the rash stage it’s so much more amenable to treatment and then more people would present to the GP and there would be more clinical experience which would help.” (Expert 13)

The latter part of this quote hints at the feeling among experts that perhaps prompt medical treatment is hindered by low awareness of ticks and tick-borne disease in the UK. General practitioner (GP) awareness of Lyme disease was a top of discussion in the majority of interviews, with experts voicing concerns that low awareness is making treatment more difficult. Some experts even gave examples of GPs who were aware of Lyme as a disease, but who were apparently misinformed about its presence in the UK:

“Someone told me their GP told them that Lyme is an American thing and you don’t get it over here, I mean if that’s the level of education of GPs then you haven’t got much hope! Luckily they’re not all that bad, but it’s a bit worrying.” (Expert 10)

Another expert talked about a survey conducted to assess GP knowledge of Lyme disease and explained the results:

“They’ve done a survey of GPs and they can have two GP practices a mile apart and one will diagnose 20 cases of Lyme a year and the other will diagnose none, simply because this GP knows about Lyme and can look for it, whereas this guy doesn’t, so it’s very...even amongst healthcare people knowledge of Lyme is patchy.” (Expert 3)

This study example also emphasises the role that experience plays in GP awareness, suggesting that those who have experience of diagnosing Lyme are more likely to include it as a relevant diagnosis in particular cases. Other experts discussed the way that geography could influence a GP’s experience as well, with GPs in tick endemic areas likely being more aware of Lyme disease, but also how GPs in urban areas also need to be aware of these issues:

“I think awareness is specific to your location because a GP in London for instance, although you could say that person should know about it because if

one of their patients goes on holiday and then comes back with a symptom and they say where they've been, what they should know is that this could be because you've been to an area where it's likely. I suppose....we're more transient aren't we, we do move around." (Expert 8)

In combination with talk about levels of experience were discussions about how medical training needs to include more about ticks and tick-borne disease so that GPs are aware of these topics and can make more accurate diagnosis regardless of geographic location.

"GPs also vary enormously in their awareness. I mean, some GPs even deny its existence here. There needs to be a huge education I think in medical students perhaps. I suppose historically there weren't that many cases and they just haven't quite caught up yet." (Expert 11)

Overall attitudes about communication

Experts were largely supportive of efforts to educate the public; however some reticence was voiced due to the potential for unintended side-effects. For example:

"I don't think there's anything to be scared of and I think ticks are so avoidable, even in high risk areas they are avoidable and it is preventable and I just think that I would rather hear those messages. I would hope that whatever advice we give doesn't result in like, people avoiding the New Forest and things like that." (Expert 1)

The concern voiced in this comment was about providing the public with information regarding both the primary and secondary preventive behaviours and fears that it may result in avoidance of the countryside. Given some of the recent campaigns to increase the amount of outdoor activities in which people engage, this could be a detrimental side effect. A number of experts talked about this fine line between scaring people into avoidance versus inciting them to practice the recommended behaviours:

"It's difficult isn't it, communicating to the public what the actual risk is because you don't want people to get neurotic about going outside, but at the same time you want them to be aware." (Expert 13)

As well as avoiding the countryside altogether, experts also mentioned that fear of disease might result in people incorrectly removing ticks and increasing their likelihood of contracting Lyme disease as the tick regurgitates the bacteria into the host:

"You don't want to make them paranoid about it so that if they do find one that's actually attached they panic because you don't want them to panic, you want them to be logical and get the thing out in the proper way." (Expert 4)

Implications for public health messages

When asked about effective ways to avoid coming into contact with ticks, many of the topic experts talked about a variety of different habitat control strategies which can be used to reduce tick populations or lower the chances of the general public coming into contact with them. While these are legitimate and effective ways to reduce tick exposure they are not the focus of this research as for the most part they are not behaviours that can be practiced by the individual. Instead, seven potential targets for a communication campaign were discussed: four primary prevention techniques and three secondary prevention techniques. Of these, tick checks were mentioned by the majority of topic experts as one of the most important ways of avoiding a tick-borne disease. Although it is important to engage in primary prevention such as wearing long trousers when out walking, these behaviours cannot guarantee that all ticks will be avoided. A tick check allows for a greater level of assurance and also helps to encourage the removal of a tick before disease transmission takes place. Communication focused on checking for and then correctly removing ticks may therefore have the best impact. Although experts were keen to stress that disease transmission is not immediate, it was clear that there is no specific time when it occurs and it could be misleading to tell the public that there is a 'window of opportunity' for removal. Instead it might be preferable to encourage removal as quickly as possible, therefore highlighting the fact that a tick check during and after outdoor activities is the best way ensure awareness of tick bites. Regarding tick removal, experts mentioned both tweezers and specifically designed tick removal tools as appropriate for safe removal. While most people will likely already own a pair of tweezers they may not even be aware that tick specific tools exist however. Ensuring that people are aware of how to remove a tick and are willing to do this must be an important component of any communications campaign.

Many of the topic experts spent time talking about the importance that both knowledge and experience play in tick avoidance. There was discussion regarding the need for an awareness of ticks before any behavioural change can expect to be instigated. Despite being topic experts who work with ticks or tick-borne disease in some capacity and know the recommended preventive behaviours, several experts still admitted that they did not practice particular avoidance strategies. Tucking trousers into socks and wearing a tick repellent were both behaviours that some experts reported that they do not and would not practice. While these experts said that they do engage in other tick protective behaviours, this still suggests that some behaviours are more popular than others even among people who are well aware of

the risks posed by tick bites. In these cases it is possible that particular behaviours are unlikely to be influenced by communications campaigns and it could be considered better value for money to focus on other behaviours where more change may be elicited.

Experts stressed the need generally for increased knowledge and awareness of ticks and tick-borne disease among the public. Taken as an overall mental model, the aspects that emerged as being believed to require more effective communication were the actual risk posed by ticks, the performance of a tick check and the timeline and technique of tick removal. Even among people who are aware of the existence of ticks, it is possible that they view ticks merely as a nuisance rather than something that could have potential adverse consequences for their health. If this is the case then it could prove difficult to encourage an uptake of tick protective behaviour given that the risk might be misperceived or downplayed. Although studies report that knowing which protective behaviours can be performed to avoid a variety of health issues is not enough to get people to engage in these behaviours, knowledge is still a prerequisite for behaviour change (Hallman et al., 2005). If there is an expectation that people should alter their current behaviour based on health recommendations then people need to know about these recommended behaviours otherwise change is unlikely to occur.

Finally, experts raised concerns about messaging potentially causing people to avoid the countryside out of fear of ticks and tick-borne disease. Avoidance of such unwanted side effects is therefore an additional factor to consider in the design of any communications material concerning ticks.

Public Interviews

Methods

Design and procedure

The interviews with members of the public were designed to generate qualitative data identifying important behavioural drivers and barriers of the primary and secondary prevention of tick-borne disease in the United Kingdom. The results from the expert interviews were used to inform the design of the public interviews. The experts provided information about which behaviours can effectively protect against tick-borne disease and suggestions as to what factors might determine their use, so the practice of these behaviours became the focus of the public interviews. All of the interviews were conducted between August and October 2011 and all took place over the phone.

In line with the King's College London ethics approval procedures (ethics approval code: PNM/10/11-110) the anonymity of each participant was maintained. As with the expert interviews, participants were provided with consent forms describing their right to withdraw from the study and the contact details of the researchers if they had any further questions after they had participated in the interview. An interview schedule was developed to cover the pathway from how a tick could end up on a human, how someone can prevent contact with ticks, about Lyme disease itself and finally, more general information about factors influencing behaviour and experience with public health communication (see appendix 4). The interview schedule acted as a guide to ensure that particular topics were covered, but topics could be discussed in any order and the interviewer used the schedule as a prompt. Each interview was approximately 30 to 40 minutes in length and was audio recorded and later transcribed by the researcher.

Participants

Participants were required to be resident in an urban area and engage in outdoor activities that might result in their exposure to ticks. For this reason, a variety of London-based outdoor walking groups were contacted by email to determine whether they would be happy for their members to take part in the study. Backabush Xplorers was one of these groups and they agreed to distribute the study details to their entire e-mailing list of approximately 2000 members. People who received this email and who were interested in taking part in the study then contacted me by email to establish a suitable time for an interview. A total of 25 interviews were conducted with members of this group.

Analysis

The transcripts were analysed using qualitative methods in the same manner as described for the expert interviews.

Results

As with the model which emerged from the expert interview data, the mental model that was created based on interviews with members of the public has been broken into two adjoining sections to represent primary and secondary prevention (see figures 2.3 and 2.4).

Figure 2.3 Public Mental Model Part 1

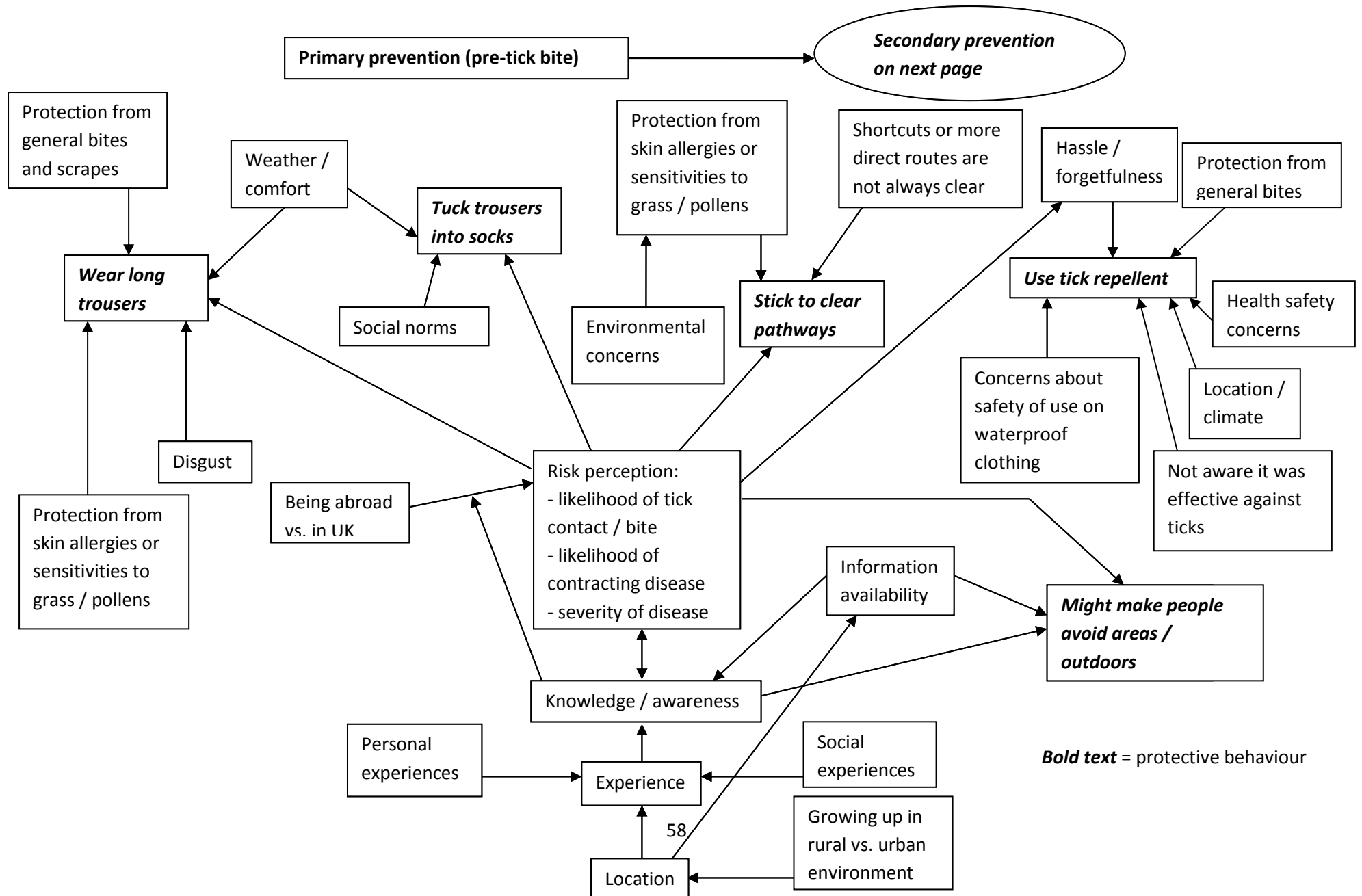
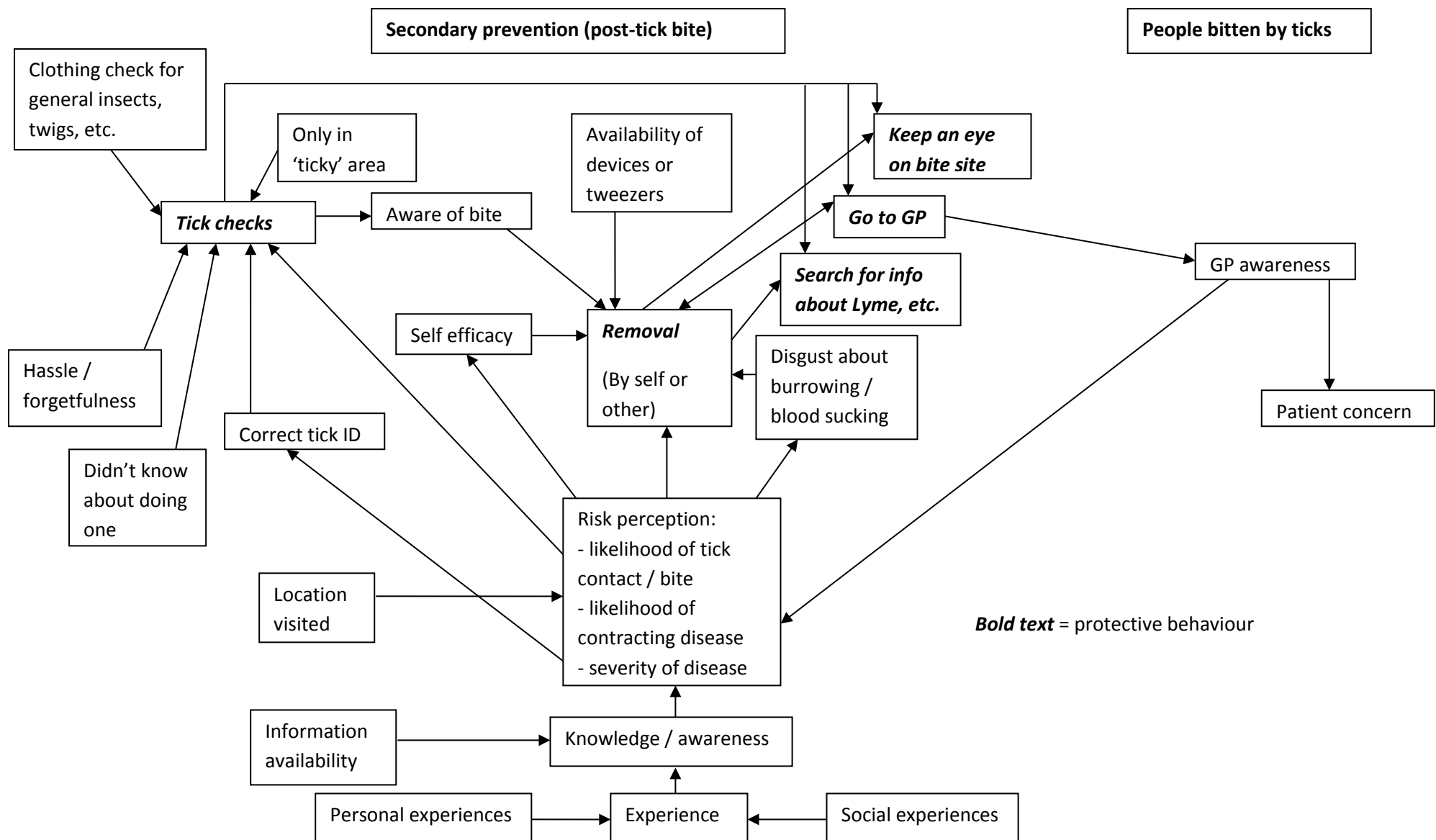


Figure 2.4 Public Mental Model Part 2



Because the expert interview results were used to guide the public interviews, the models are similar in their structure. The expert interviews highlighted the particular protective behaviours that can be practiced in order to avoid tick-borne disease and these were used as the basis for the public model. The behavioural prevention strategies have been discussed already in the expert interview section. This section therefore focuses on the motivators and barriers for these behaviours.

Primary prevention

Although there were behavioural barriers that were mentioned specifically with regard to particular primary prevention behaviours, there were also drivers that had a more general behavioural influence. These were experience, knowledge etc. These overarching factors are therefore discussed first, followed by factors that were more specific to particular behaviours.

Experience

Experiences, both personal and social, related to ticks came up repeatedly during the interviews. People talked about having never come across ticks before and how this lack of experience made them feel that there was not really any need to take precautions:

“I’m open to the idea that my attitude perhaps may be complacent because I’ve not encountered ticks. But if I started finding more ticks on me when I went out or started finding people in my group experiencing more tick issues, or if there were reports in the media of more serious tick problems...then maybe I’d take more care” (Participant 1)

“I wouldn’t say I go to any great length to prevent myself from coming across ticks, probably because I’ve never been affected by ticks. If I was to, then of course I probably would.” (Participant 4)

The interviews revealed that in addition to personal experiences, social experiences can also influence a person’s knowledge and awareness regarding ticks and the potential risks that they can pose:

“...if somebody had told me about their own experience that might encourage me to take more precautions. (Participant 12)

...do other people in your hiking group, do they take any precautions against ticks that you know of?

Not that I know of, I think probably quite a lot of people I know have a similar attitude as myself.” (Participant 22)

Other people talked about their experiences of having come across ticks or being bitten by ticks during childhood in a rural area, highlighting how location can play a key role in shaping people's experiences with ticks:

"I grew up in the countryside so it was something that was always drummed into us as kids to avoid walking in bracken and to put long trousers on and that where there are sheep and animals and you have to walk in bracken just make sure you're well covered." (Participant 2)

Participants also speculated about how they thought that a person's location in either an urban or rural environment could impact their experience of ticks and in turn their knowledge or awareness of potential tick risks:

"So the majority of people certainly live in urban situations and aren't aware of what these things can do...you set off from your city for a day in the country and actually they're not aware that these things do exist and what they can do." (Participant 11)

Asking participants to describe any tick related experiences often led to discussion of what they knew or thought they knew about ticks and the risks that they could pose to people. As might be expected, the amount of information that people provided appeared to be related to their level of experience, with those who provided the most information demonstrating more experience of ticks than those who provided less information.

Knowledge and awareness

Participants were asked about knowledge of any tick protective measures and Lyme disease. There did seem to be some knowledge of potential tick protective behaviours, however there also appeared to be a lack of awareness about the importance or effectiveness of these behaviours. Participants were also asked about whether they had come across any information sources about ticks or Lyme and if so where this had been located and their perceptions regarding the information. A number of people mentioned that they knew of ticks or Lyme, but none of the details:

"I honestly haven't come across any leaflets that I can recollect. Obviously I have heard of Lyme disease, but probably my knowledge about it is actually pretty limited." (Participant 1)

Others said that they had seen signs or information in particular areas such as Richmond Park and that they felt these kinds of reminders may have prompted them to be more aware of ticks:

“it’s not a standard thing on every walk or in every group that I have been made aware of it and certainly in some parts of Europe there’s been sort of signage and information or maybe I was more, again because I’m abroad I’m probably more kind of careful and in the book it probably said like, ticks are a problem here, so...” (Participant 22)

Some participants reported that they had never come across any information regarding the risks posed by ticks, even from sources that they might have expected would inform them:

“I’ve been walking with different adventure groups and I don’t get anything from them [information about ticks or tick-borne disease] either.” (Participant 2)

Discussions of information availability and whether more information needs to be made available to the general public led some participants to voice concerns about the possibility of information provision actually having an undesirable effect of causing people to avoid the countryside or outdoors:

“I think by putting things in a mass media that would put people off that have children and would go walking in the country and parks and they would then become worried. If it’s done for the more serious groups that go out into forests, etc, then I think it will be treated as information for them.” (Participant 20)

Another participant countered this view by pointing out that they felt it would be better to have some knowledge than none at all:

“I don’t think it would put people off necessarily, but sometimes, I’m thinking that if I go somewhere and say I did get some bites, if I didn’t know about ticks and I got this thing burrowing into my skin that would really freak me out. So I think having no knowledge is sometimes a bit dangerous or might put people off more than knowing something like saying look, this area is safe to walk in if you take precautions like covering yourself up because there are ticks.” (Participant 2)

Even among participants who were unsure about how sensible providing information about tick risks to the general public as a whole was, there was a feeling that information would not cause avoidance among members of outdoor groups. Every participant interviewed said that they would not stop engaging in outdoor activities because of ticks since the outdoors is a large part of their personal or professional life:

“No, I mean it would take a serious risk to prevent me from going out into the outdoors...I’m an outdoor professional and the outdoors is my livelihood.” (Participant 1)

Participants commented that because of their love of the outdoors that if necessary, they would be more inclined to take preventative measures against ticks than to avoid tick risk locations:

"I would take more prevention measures rather than avoid the outdoors."
(Participant 3)

"I mean I use sun cream when the sun's out so it's that kind of thing...if you're aware of the danger then you can do what you can to minimise it, but it certainly wouldn't stop us going outdoors, no." (Participant 11)

Risk perceptions

Each interview was spent talking to participants about their perceptions regarding ticks and tick-borne disease. Participants seemed to have a particular interest in the likelihood of both coming into contact with a tick and being bitten by a tick as well as the likelihood of contracting a disease and the potential severity of the disease. A lot of the discussion centred around a feeling that people did not know a great deal about ticks or tick-borne disease and were unsure whether it was something that should gain their consideration, but suggested that if it was then they would generally be happy to take precautionary measures:

"I think if I was walking in an area that I thought there was a really high threat of ticks, I think I'd be really cautious and walk with long sleeves and trousers and what not, do thorough checks." (Participant 14)

Participants' perceptions of the risk and what they think they know about it therefore appear to be an important determinant of whether or not they choose to engage in tick protective behaviours. For instance, when one participant replied that they would not consider tucking their trousers into their socks when walking in the countryside they were then asked why they thought this was and they responded:

"....why wouldn't I do it...well maybe I'm thinking of the incidence of a tick to me would be very slim really." (Participant 13)

Other participants explained that they perceived the risk of ticks to be too low to consider taking precautions, or felt that the risk of ticks was low on the list of general concerns:

"I don't really think there's a risk of getting a bite here." (Participant 12)

"I probably do way more risky things than worry about ticks." (Participant 10)

Tick risk perception was also largely dependent on a person's location. When asked about whether they practiced precautionary behaviour, a number of participants said that they do, but not when they are in the UK:

"To be honest I didn't realise that there was the potential threat of Lyme disease to the extent over here that there is in North America. So because of that I haven't, I don't really take any precautions [in the UK]". (Participant 14)

Another participant explained that knowledge of tick habitats and locations could be an important factor in driving precautionary behaviour because people who are visiting the UK or who have moved to the UK from another country may not be aware of the potential health hazards:

"That would be useful to have, to highlight more the um, the more high incidence areas. I've noticed that it's mainly where there's deer, but if you're not familiar with parts of England you wouldn't really know." (Participant 13)

While the tick prevention behaviours are all influenced in part by location, experience, knowledge and risk perception as evidenced above, they are also each influenced by a set of unique behavioural barriers. These barriers are not necessarily an exhaustive list, but all were mentioned by at least one participant during the interviews with members of the public.

Strategy 1: Wearing long trousers

Wearing long trousers when out walking was frequently recommended during interviews with topic experts as an easy and effective way of avoiding contact with ticks. Although some public participants reported wearing long trousers when walking, they gave a variety of reasons for this which were unrelated to avoidance of ticks. One of the most common reasons discussed for wearing long trousers was to provide protection from general bites and scrapes:

"I do always wear long trousers, but in truth it's probably more because there's always stinging nettles and gorse, rather than being specifically worried about ticks, although I mean it does cross my mind from time to time." (Participant 1)

"I usually do wear long trousers, but not....um, more because of the brambles and the scratching of legs than ticks." (Participant 20)

Similarly, another participant explained that they choose to wear long trousers when walking because it provides them with protection against skin allergies or sensitivities from a variety of grasses and pollens:

"The other reason I guess why I wear long pants is because I can walk through grass and sometimes it will irritate my skin." (Participant 25)

The decision to wear long trousers was also mentioned as being dependent upon the weather forecast and the desire to be comfortable while walking or rambling:

"It very much depends on the weather. If it's really baking hot it's really difficult to get anybody to wear long trousers." (Participant 11)

"I would be in long trousers if it was from probably November through to February, but the rest of the year I would wear shorts." (Participant 7)

For one participant a combination of weather and protection from vegetation were the reason for wearing long trousers:

"It depends what the terrain is like, but in hot weather I'd wear shorts." (Participant 6)

One participant explained that because they are a bit disgusted by ticks this makes them keen to practice protective behaviours such as wearing long trousers in order to increase the chances of avoiding a situation where they are actually in contact with a tick:

"Yeah, I wear long trousers and that kind of thing and make sure...I'm very wary of them actually because they kind of freak me out a little bit." (Participant 10)

Strategy 2: Tucking trousers into socks

In addition to recommending that people wear long trousers when walking or rambling, experts also said that tucking trousers into socks could help to stop ticks from coming into contact with bare skin. As with wearing long trousers in the first place, this was dependent upon weather and personal comfort:

"I wouldn't wear long trousers in hot weather...I wouldn't tuck them in or anything." (Participant 6)

The most important and influential driver behind whether someone said that they would tuck their trousers into their socks was social norms. When asked why they would not consider performing this behaviour a number of participants explained that it was because of how others would perceive them:

"What about tucking your trousers into your socks?

I don't do that.

Ok, is that something that you would consider doing?

No cause I'd look stupid." (Participant 2)

However, in a situation where the risk of tick-borne disease is perceived as a real threat and where other friends or members of the public are practicing the behaviour, it can become a socially acceptable thing to do:

"And have you ever tucked your socks into your trousers as a way to stop ticks getting on your bare skin?

Not over here, but in the States I have, but not over here.

So when you did that in the States it was specifically to avoid ticks?

Yeah it was, it was to take precautions.

And were the people you were with doing that as well?

Yeah and there was, you know there were signs up warning that there was a prevalence of ticks and stuff." (Participant 14)

Strategy 3: Stick to clear pathways

Another method for avoiding ticks as recommended during the interviews with topic experts was to avoid walking through long grass and to stick to the cleared pathways when walking or rambling. Many participants reported that they did at least try to stick to cleared pathways; however as with wearing long trousers, the reasons for this behaviour were not necessarily related to a desire to avoid contact with ticks. One participant was concerned with the potential environmental impact of leaving the beaten track:

"I stick to clear pathways so as not to damage the environment. I wouldn't do it for ticks." (Participant 6)

Another participant cited potential allergic reactions as a driver for avoiding longer vegetation:

"I tend to try to avoid long grass cause usually I do marked walks, so like a walk out of the ordinance survey book which will probably be following the path and sometimes when I have gone walking through long grass I have a reaction, almost like an applied metal rash where the grass has touched me." (Participant 15)

Others pointed out that while the intention is to keep to cleared pathways when walking or rambling this is often easier said than done:

"I suppose mostly on the path, but you get lost and end up going through some bushes and things!" (Participant 5)

“We’ve also got lost and had to cut through someone’s field and as much as you try to hug the outside of the paddock, you still do end up walking through longer grass than you really would like to.” (Participant 25)

Even among participants who were not talking about a time when they had gotten lost and had to traverse through longer vegetation there was discussion about the fact that even the way-marked paths are not always kept clear:

“Sometimes the paths are overgrown because they’re not necessarily that well maintained.” (Participant 3)

In this way, even when people do stick to their route they may still brush past foliage and potentially come into contact with ticks, suggesting that this particular avoidance behaviour may be best practiced in combination with other strategies.

Strategy 4: Use of repellent

Using repellent was another behaviour that topic experts recommended as a way to reduce or avoid contact with ticks. It was also the primary prevention behaviour that garnered the most discussion in terms of behavioural barriers. As might be expected, the topic of repellent use raised health concerns for some people. Several participants suggested that because of health concerns they would choose other tick prevention behaviours over a repellent if necessary:

“Probably I’d try to avoid using too much DEET because it’s not very good for you and so probably I’d just be more careful about wearing long trousers and you suggested tucking them in and things like that so I’d got for that kind of thing more.” (Participant 23)

Another participant had a different view point, explaining that they use repellents such as DEET against mosquitoes, so if they perceived that ticks were really a problem then they might consider using the same precautions against them:

“I mean I’m always reluctant to use DEET because it seems like such a harmful substance and not great for your skin perhaps, but yeah, I mean if they were a problem I certainly would use it as I do for mosquitoes.” (Participant 7)

As with the above participant, there were a number of people who reported that they use repellents already, but not necessarily because of ticks:

“I’m a favourite of flies and anything, they love to bite me. I cover myself now in jungle formula.” (Participant 2)

There were also those participants who reported using a repellent, but only when abroad due to their perceptions of tick risk in the UK:

"I tend not to use insect repellent much in this country...I tend to only use in malarial countries." (Participant 3)

"Well we do use insect repellent for mosquito bites and general stuff like that or if we're in hot climates, but we tend not to use it in Britain because we don't really have a hot climate. It may be ignorance on our parts, but we're not really aware that that's a major problem over here." (Participant 11)

Other participants said that they have used repellent or would use it, but that they have trouble remembering to do so, especially if they are involved in activity that has not necessarily been planned in advance:

"Yeah and I think I'd tend to forget to carry those kind of things as well. I tend to go out walking ad hoc without kind of always planning it." (Participant 14)

"Yeah, but I'm very forgetful so I don't always remember to take it [repellent] with me particularly if I'm running." (Participant 18)

It was suggested that it might be easier to remember to apply a repellent if people knew more about the risk of ticks and also if the behaviour could be built into a routine action:

"Yeah I guess it's more remembering, like for me it would be building something into a routine like putting sun cream on before you go and lay out. It would be kind of spraying or whatever it would be so I guess it would be remembering that advice and actually knowing what the consequences of being bitten by a tick would be. So for me taking precautions and I think it would be helpful, but also to have something that's easy to carry around." (Participant 10)

A number of other participants did not use repellents at all due to concern about the effect it could have on waterproof clothing:

"I must admit I'd be a little reluctant to use a repellent like DEET that can be quite toxic, or to the best of my knowledge is supposed to be quite toxic, again these may be wrong beliefs but I've also been told that DEET can cause damage to the GORE-TEX membranes of waterproof clothing because it's supposed to be sort of aggressive on plastics." (Participant 1)

Most said that they were unaware that repellents were available or effective for use on ticks:

"The only time I've used repellent is when there's a lot of mosquitoes around. I've never thought of using DEET specifically for ticks, but I think that's because I've never come across them." (Participant 7)

Secondary prevention

Figure 2.4 shows the second half of the public mental model and as with the expert model it is focused on the post-bite or secondary prevention stage. The bottom of the model includes many of the same behavioural drivers as were discussed regarding the primary prevention stage. Although these factors appear similar to the primary stage, they were specific to the secondary prevention behaviours of performing a tick check and the quick, safe removal of a tick if bitten. As before, these can be split into those that are general across behaviours, and those that are specific to certain behaviours.

Experience

One participant explained how their experiences with ticks had shaped their behaviour:

"I have done tick checks myself, but again not in the UK. If my responses are honest then I guess I'm perhaps tick complacent in the UK having never been bitten by one in the UK I'm not overly concerned about it." (Participant 1)

Knowledge

Another factor that was deemed an important for influencing whether or not someone practices secondary prevention strategies was knowledge of ticks and tick-borne disease, but primarily having this information readily available:

"Um, if there was a risk, if there was a study showing that, well you know, that there was Lyme disease out there then yeah, I would perform checks and stuff like that and if I was walking in an area and there was a sign up to say you know, beware of ticks, then I would be more cautious and also check and everything. But I've not see, you know, I can't think of anywhere I've been in the UK that there is sort of warnings." (Participant 14)

A number of participants independently came up with the suggestion that it would be useful to have such information available through their walking group

"I think it would be more useful to have it on the actual site of the organisation you're going out walking with or conservation bodies would be useful because if you're going somewhere you might just see it on their website and think I ought to be prepared, but what's that about, you're unlikely to search for it unless you're interested." (Participant 18)

"For me it would be more through my group. So yes if there was something that they put on their site then I would read it, I wouldn't probably look for that information." (Participant 20)

Risk perceptions

Tick checking and removal behaviours were also mentioned in connection with personal beliefs about tick risk perceptions. For example one participant stated:

"I don't think anybody's going to do anything about it unless they know what the effect on them is going to be. I don't think people would take preventative action unless they knew what it means for them." (Participant 15)

Also important were perceptions of disease severity and how someone could be adversely affected by a tick bite:

"I have a friend who's recently been diagnosed with Lyme disease and it's taken like a good three years for it to sort of be diagnosed and he's in a pretty bad way so it's quite eye-opening you know, the sort of potential danger that it could pose and I guess the whole thing about the bulls-eye rash and making sure you check." (Participant 14)

As with the primary prevention stage each of these factors (experience, knowledge and risk perception) influence the engagement with particular behaviours that the public can perform to protect themselves from ticks and tick-borne disease. While the primary preventive behaviours discussed in the interviews can be largely independent in terms of whether someone practices them alone or in combination, the secondary preventive behaviours occur in a particular sequence.

Strategy 1: Performing a tick check

The first phase of secondary prevention is performing a tick check. This behaviour has been recommended by topic experts because although someone may practice one or all of the primary prevention behaviours, it is still possible that they may have come into contact with a tick. Of course, in order to perform an accurate tick check, it is necessary for people to be able to correctly identify a tick. Although some participants reported that they knew what a tick looked like, others were unsure:

"I'm only vaguely aware of what a tick is. I knew it was an insect." (Participant 6)

"I think it would be good to have more pictures because sometimes people don't know what they [ticks] look like." (Participant 9)

Another potential barrier that participants pointed out with regards to whether or not they would perform a tick check after rambling or walking is a lack of knowledge about what a check is, how it should be done and that it needs to be done at all. Among

those participants who had heard of tick checks there was also a concern that they would forget to practice the behaviour:

"Ok yeah, so you've just never thought of it as something that you might need to do or..."

No, no. I mean I guess if I was walking somewhere like say I was going to a park here or something and there was a warning sign about it then yes I would make sure to do something but if there's no warning sign then it wouldn't actually enter my mind to think about doing anything." (Participant 21)

As with some of the primary prevention behaviours, an influencing driver that participants reported as having an impact on whether they would perform a tick check would be their ability to remember to engage in the behaviour and the time it takes to perform:

"I think normally when you get back from a walk you're tired and you just want to kind of have a shower and..." (Participant 22)

Other participants did say that they perform a check after walking or rambling; however this is not specifically for ticks, but for general vegetation or other items with which they may have come into contact:

"I wouldn't necessarily check my legs every time, but I think probably somewhere in the back of my mind I do kind of subconsciously look, not just for ticks, but for anything else that's become attached to you if you've been walking through long grass." (Participant 7)

"Well, I mean I check out my clothes anyway when I take them off to make sure because usually there's grass or vegetation or something on them so I shake them outside." (Participant 13)

Several people mentioned that they have performed a tick check before, but that this was primarily when they were abroad, or when they knew that they were in an area where ticks are abundant:

"I have done tick checks myself, but again not in the UK. It's more when I've been abroad and I've discovered oh my goodness, there are lots of ticks there and I have got ticks on me and then you start realising, ok I'm in tick country." (Participant 1)

"Say someone I was with said, 'oh god I've got a tick on me', then I would check myself, but as a general rule, no...unless we've been walking through some particularly overgrown areas...but I'd check the dog first rather than me to be honest." (Participant 3)

Strategy 2: Tick removal

When someone realizes that they have been bitten by a tick then the next step of disease prevention is to make sure that the tick is removed quickly and safely. A person's experience regarding ticks and tick-borne disease play a large role in determining whether someone feels confident in their ability to appropriately remove a tick. This was described by numerous participants; for instance, someone who had previously been bitten by ticks and removed them reported fairly high confidence in their abilities:

"Well I've had ticks on me before so yeah, I would be confident enough to remove it, yeah." (Participant 1)

As did a participant who had experience removing ticks from their dog:

"Yeah [I would feel confident]. I've had quite a bit of practice with the dog." (Participant 3)

Whereas those who had little or no experience of ticks reported lower confidence regarding removal abilities:

"I'd probably have a small panic and get it stuck in my leg or something!" (Participant 5)

In addition to experiences, self efficacy about tick removal was also related to knowledge regarding how to best carry out the removal process:

"...the information I do know about trying to remove them, it still seems sometimes kind of mixed messages. Some people tell me that you used to be able to put Vaseline on them and that would be fine and they do that, but the people have also told me that you shouldn't do that anymore." (Participant 9)

Comments were also made about the availability of the specific tick removal devices:

"I have actually seen them now in the outdoor retailers." (Participant 1)

Also influencing whether or not someone is likely to engage in safe and appropriate tick removal is a component of disgust. A number of participants talked about how their feelings of disgust towards ticks and tick bites would potentially affect their ability to remove a tick. Disgust seemed to primarily stem from the fact that ticks are associated with blood and being difficult to remove:

"I think the thought of them burrowing into the skin and I can remember it wriggling about." (Participant 2)

“Just kind of anything wriggly like that and that can go into your body and feed off your blood...it’s horrible. It’s like mosquitoes isn’t it, it’s horrible. Feeding on your blood...the thought makes me feel really itchy!” (Participant 4)

There was also a suggestion from one participant that having had experience with ticks could actually make one become desensitized to the disgust associated with tick bites and tick removal:

“Um, I would describe my reaction of disgust as mild. I guess most people probably are quite disgusted...perhaps I’m a bit more desensitized by experience.” (Participant 1)

Several participants also said that they felt that they would need to get someone, possibly even a GP or medical professional, to help them to remove the tick because they would feel too upset to do it themselves:

“I’m quite squeamish anyway so I’d probably have to get someone to help remove it because I don’t actually know what you’re meant to do.” (Participant 22)

Further strategies: Keep an eye on bite site, visit GP and seek information

The actions of performing a tick check and removing a tick both lead to a series of other secondary prevention behaviours. A number of people mentioned that they would be keen to keep an eye on the area where they had been bitten by the tick:

“Oh yeah, I would [keep an eye on it], just in case any kind of infection occurs or anything.” (Participant 13)

“Um, if it was on me I’d probably keep an eye on it, um, usually if it’s like...I’ll know in a couple of hours whether my skin’s, you know, whether I’m reacting to it because I’m quite, I have quite sensitive skin.” (Participant 25)

Other participants talked about going to see their GP either to have the tick removed:

“Um, I think you’re not supposed to take it off yourself and I’d probably go to the doctor.” (Participant 18)

“I’d probably go to the GP because it’s something I’ve never dealt with and I’d be worried about leaving half of it in me.” (Participant 20)

Or post-removal to have a general check of the tick bite site for peace of mind:

“I’d probably go to my GP for a check. Even just the thought of it makes me feel quite ill.” (Participant 2)

If a tick was found during a tick check the first thought that most people had was about removal, but following removal there were a number of participants who

mentioned that they would then start looking for information about ticks and tick risks:

“I think to be honest if I was ever bitten by a tick and I knew about it the first thing I would be doing is looking up diseases and, only because I already know Lyme disease is linked to it I would definitely go and look it up and you know, what to look out for.” (Participant 22)

Concerns about GP tick awareness

Although these are all of the secondary prevention behaviours that were discussed as potential ways to mitigate tick risk among the public, the model does also include the aspect of GP awareness regarding ticks and tick disease risk. A number of participants had had experiences with tick bites and had sought medical attention for this in the past, therefore providing information about how they were treated by medical professionals and what information they had been given about how to deal with ticks and the potential consequences. Participant experiences highlight some potential gaps in GP tick awareness in the UK:

“They did, he [the GP] gave me a leaflet about Lyme disease and quick removal, but he did also tell me that...not to worry so much about the Lyme disease because it’s hyped up a lot...were his words to me.” (Participant 9)

“I took him to the doctor’s on the Monday and he told me signs to look out for, but he was generally healthy and didn’t seem to be suffering, and then he sprayed the tick three or four times and he expected it to drop off straight away but it didn’t and it did eventually take 2 to 3 days for it to fall off and I just kept an eye on him, but he wasn’t feverish, he wasn’t overly tired...he said to look out for flu-like symptoms which he didn’t show.” (Participant 11)

While these are the quotes of only two people, they do raise the issue of whether medical professionals in the UK are suitably aware of potential tick risks that exist and correspond with similar comments made by the topic experts. This is an important question to answer as awareness and attitudes among the medical profession could potentially impact attitudes among the general population with regards to perceptions of tick risk and the need to engage in preventive behaviours. GP awareness can also affect the level of patient concern:

“I’ve had times when I’ve had rashes and I don’t know where they’ve come from and neither did the doctor, but now that you’ve told me about that I realise it could have been that and I’ve also seen on other people the same kind of thing...it looks like ring worm but it’s not and obviously if you don’t know about it then you don’t know to check for it.” (Participant 17)

Discussion

The use of the mental model approach highlights the importance that should be given to public input when designing a behaviour change campaign. Even a cursory look from the topic expert to the public mental model makes it obvious that the public model contains far more detail. Interviews with topic experts produced a list of recommended, effective tick prevention behaviours; however experts were less forthcoming when asked about what they felt might drive members of the public or themselves to engage in these behaviours. It is possible that this could have been because the various professional roles that many of these experts have are focused on aspects of understanding ticks and tick-borne disease rather than actively changing public behaviour towards ticks. Although topic experts did report behavioural drivers and barriers for most of the recommended prevention behaviours these did not always match what came out of the public interviews and in many cases the public reported behavioural drivers and barriers that had not been considered by topic experts. All of this indicates that while topic experts are crucial for providing guidance about the most effective strategies for avoiding and mitigating the risk of ticks and tick-borne disease, there needs to be engagement with the public about why these strategies do or do not work. For example, the 2008 study by Gould et al., as described in chapter 1, found a decrease in knowledge and a reduction in risk perceptions regarding the likelihood of contracting Lyme disease in one of their study populations following the distribution of intervention materials. Although the authors had engaged with the public in the study, they did not follow up with any investigation into the reasons surrounding the failure of the interventions.

Based on the interviews with both experts and members of the public, it appears that tick checking behaviour is the ideal point of focus for behaviour change materials. While the other preventive behaviours are certainly worth promoting to the public, they are likely to be less amenable to change and are potentially less useful in comparison to a tick check. In addition, although we do not have data from a rural population, the focus on an urban population that interacts with the rural environment has been supported by the interview data which has shown low levels of knowledge and limited reports of preventive behaviour. By focusing on this particular population it should be possible to see a greater increase in the uptake of protective behaviours than might be the case in other, more experienced or knowledgeable populations. Furthermore, urban GPs may be less familiar with ticks and tick-borne disease, making education of the urban at risk population even more important.

Tick knowledge and awareness were discussed in detail in both the topic expert and the public interviews. Experts spoke about the need for increased awareness regarding tick identification and appropriate prevention behaviours, particularly the performance of tick checks and tick removal. These needs were largely reiterated among members of the public. As mentioned earlier in this chapter, unsurprisingly, knowledge and awareness of ticks appear to be linked. The interviews highlighted the fact that some people are unsure what a tick is or that it can pose a risk to humans in the UK. There also appeared to be a lack of awareness about what a tick check is and what it entails and confusion over the best way to remove a tick if bitten.

Discussions about increasing awareness were not limited to members of the general public, but also applied to medical professionals. Both experts and members of the public reported experiences where they felt that medical professionals lacked the knowledge to deal with ticks or tick-borne disease appropriately. A previous study in a tick endemic area of the United States found that general practitioners displayed good general knowledge of Lyme disease, but awareness of symptoms was lacking (Magri, Johnson, Herring, & Greenblatt, 2002). It is likely that this awareness may be even lower in non-tick endemic areas, particularly within the UK given that there have been fewer awareness campaigns compared to the US as described in chapter 1. This lack of awareness has a knock-on effect for the general public who may seek advice or treatment from a health professional such as a general practitioner. The potential danger is that incorrect information could be passed on from professional to public and this is hard to redress.

Public risk perceptions weighed heavily in each interview. Members of the public seemed to place particular importance on knowing the details of tick and tick-borne disease risk. Questions were raised about the severity of Lyme disease including specifics about how it is contracted, what the symptoms are and how quickly it can progress. Participants also wanted to know about the likelihood of coming into contact with ticks. There appeared to be a lack of awareness about where ticks can be found, both in terms of habitats and geographical locations, with participants wanting to know how prevalent ticks are and whether this varies by place. Finally, uncertainties about the likelihood that being bitten by a tick could result in disease were common with many participants wondering whether all ticks carry disease or perhaps just a small proportion. Providing more direct answers to these questions may help the public to form more accurate perceptions of the risk posed by ticks and to alter their behaviour accordingly. On the other hand, interviews with experts suggested that they harboured some apprehension that providing too much detail about disease risk or severity

could cause greater concern among the public and be detrimental to the uptake of the desired protective behaviours; however the current literature does not seem to support this concern. A longitudinal study conducted in a tick endemic area of the United States determined that participants who had reported a higher level of risk perception at the time of initial contact were much more likely to have received the Lyme vaccine at time of follow up than those with lower risk perceptions (Herrington, 2004). Furthermore, those who received the vaccination experienced a reduction in risk perceptions. The importance of risk perceptions in driving behaviour change is not specific to a tick-borne disease context, but has been shown by research into a variety of health issues such as sun protection and SARS (Branstrom, Kristjansson, & Ullen, 2006; Cava, Fay, Beanlands, McCay, & Wignall, 2005).

Chapter 1 provided a review of nine studies studying the impact of any communication-based public health intervention on the practice of tick protective behaviours. These interventions ranged from before and after studies providing participants with an information leaflet (e.g. Jenks & Trapasso, 2005) to more complex randomised controlled trials providing participants with a variety of different intervention materials (e.g. Daltroy et al., 2007). Regardless of the intervention strategy and style, each study reported an increase in levels of knowledge surrounding ticks and tick-borne disease. The more in depth studies that measured behavioural change as well as level of knowledge provide some indication that successfully increasing knowledge and awareness about ticks and tick-borne disease can help to facilitate a positive change in the uptake of tick protective behaviours. In line with the findings from the literature, the role of knowledge as a key driver of behaviour change was highlighted again in the qualitative research discussed within this chapter. Interviews with both the topic experts and members of the public resulted in discussions about the importance of knowledge for behaviour change. This knowledge could be as simple as being aware that tick protective measures exist to a more detailed knowledge about what ticks are, why they are a potential risk to humans and why it is important to practice protective behaviours. Clearly having access to the correct knowledge regarding ticks and tick-borne disease is important, but by itself this knowledge may not necessarily translate into successful behaviour change.

Tick removal was a topic that was discussed by both experts and the general public with differing results. Experts expressed reluctance to provide the public with too much information, particularly about disease risk and severity as there was concern that this could make people panic and remove a tick incorrectly and therefore increase the risk of disease transmission. However, members of the public reported high levels of confusion about the

best way to remove a tick and expressed a desire for clearer information in order to help them with the removal process. Among those who reported being bitten by a tick, several had sought medical attention because they were unsure what to do or how to safely remove the tick. Other participants who had not been bitten reported that they would seek medical attention if they were bitten because they would not feel confident about how to go about the removal process. The provision of clear, concise information about appropriate tick removal could potentially reduce panic among members of the public by increasing feelings of self-efficacy toward removal. In fact, previous research has shown that the provision of health education can be an important driver of self-efficacy (Kok, de Vries, Mudde, & Strecher, 1991). In addition to increasing knowledge about how to go about appropriately and safely removing a tick, it is important to make removal devices widely available and easy to find.

The thought of removing a tick also raised emotions of disgust among some members of the public. Ideally it would be useful if disgust drove people to perform tick protective behaviours in order to avoid the perceived unpleasantness of the tick removal process. Following the interviews there was some indication that disgust might drive behaviour in this way; however it was unclear whether it may also have the undesired effect of making people avoid performing a tick check because they do not want to find a tick and have to deal with removal. The theory of a behavioural immune system as outlined in chapter 1 suggests that disgust acts as a motivator for people to try to avoid coming into contact with potential sources of infection (Schaller & Duncan, 2007). While the interviews in this study provide confirmation of previous research that ticks do elicit a feeling of disgust among members of the public (Prokop & Fancovicova, 2010), perhaps disgust as a barrier to tick removal is in fact in line with behavioural immunity.

Interviews with members of the public made clear that engagement in some of the protective behaviours recommended by topic experts is driven by a variety of factors that are unrelated to a desire to protect oneself from ticks or tick-borne disease. For instance, numerous participants explained that they do wear long trousers when they go walking or rambling for the reason that they afford protection from general cuts and scrapes. Identifying and understanding these non-tick related behavioural drivers is just as important as identifying and understanding those that are directly tick related as it provides a picture of how best to successfully encourage the uptake of preventive behaviours. It is also possible that these other behaviours might serve as cues to action, or reminders to engage in tick protective behaviours. For example, someone who already engages in checking their clothes or kit for

ticks or other debris may find it useful to use this as a link to performing a tick check of their body as well.

In addition to concerns held by topic experts that the provision of detailed information about ticks and tick-borne disease could potentially cause panic among the general population, there was also a concern that it could result in an avoidance of the outdoors. Although a few members of the public mentioned this as a possible side effect for other people, when asked directly whether they would ever avoid the outdoors due to concern over ticks every participant stated that they would not.

Methodological limitations

It is important to note that the mental models that have been formed as a result of these interviews do not necessarily provide an exhaustive list of all tick protective behaviours and their drivers, but is instead a representation of all behaviours and drivers mentioned during the course of the expert and public interviews. It is possible that other behaviour barriers and drivers do exist and have failed to be captured here, but the models produced from this study are a fair representation of the situation in a UK context and this particular population and as such are accurate and useful sources of information for the creation of targeted public health messages.

The interviews with both topic experts and members of the public provided a large amount of in depth and detailed qualitative data. The purpose of this phase of data collection was not to quantify any relationships, but rather to understand the process surrounding a tick bite and more crucially, the drivers and barriers behind tick protective behaviours. Although the interviews were useful there are always limitations to qualitative data. Firstly, interviewing someone, whether they are an expert in their chosen field or a member of the general public, is a social process which means that the process is unpredictable and constantly changing. Each person has their own way of communicating and this means that there is some inconsistency in each interview. Although the same interview guide was followed with each participant I may have asked a question slightly differently to each person and the interviews would have differed based on the personal experiences of participants. In addition to this, the questions or terms used in the interview may have been interpreted differently between people. For example, people may have differing ideas about what a tick check is and how to perform one. In order to minimize this sort of problem there were a series of follow up questions where participants were asked to provide more information or explanations about

their answers to ensure as much clarity as possible. Secondly, there is the possibility of a responder bias with participants providing the answers that they thought I would want to hear. Individual participants may have done this either consciously or subconsciously, but overall I think this bias will have had little impact on the qualitative results because most participants still reported that they did not engage in a many of the tick protective behaviours. Thirdly, it is impossible to generalise based on these results and there is no way to statistically test the strength of the findings. However, the results do provide useful guidance for future research by highlighting areas that can be explored in more detail in the following, quantitative stage of research. Finally, it is worth mentioning that given that all participants were members of an outdoor group it is likely that their answers reflected an interest and importance placed on engaging in outdoor activities. It is possible that responses could differ among the larger general public and could result in a need to tailor information accordingly.

Links to theory

Psychological theories of behaviour change including the health belief model, protection motivation theory, the theory of planned behaviour and social cognitive theories were discussed in chapter 1. These theories were then incorporated into the design of the interview guides which means that the results of these qualitative interviews can be clearly linked to each of the theories. Looking at the mental models it is possible to see that theories are relevant to tick protective behaviour, both in terms of how the different aspects of these behaviours might be informing and shaping theories, but also with regards to how the theories might be useful in changing behaviours. The health belief model addresses aspects of how an individual perceives a health threat, perceptions of their ability to practice a behaviour and their perceived barriers and benefits towards the behaviour (Abraham & Sheeran, 2005). Interviews with both the topic experts and the public resulted in discussion about how knowledge and experience appear to be important influencing factors on individual threat perception regarding ticks and tick-borne disease. In these interviews, self-efficacy was clearly shown to be a driver in the tick removal process given that many participants talked about their lack of confidence in their own ability to remove a tick if necessary. Numerous barriers to each protective behaviour were also discussed and are clearly evident in the mental models. Protection motivation theory has many of the same elements, but also includes response efficacy (Cameron, 2009). Participants expressed different levels of perception about whether they felt that tick protective behaviours were necessary, but also about whether the behaviours themselves were effective. The theory of planned behaviour encompasses these

elements, but also goes further to say that people's perceptions about how others would view them if they engaged in a behaviour plays a role as well (Connor & Sparks, 2005). This was particularly evident with regards to the recommended behaviour of tucking trousers into socks when participants said they would not engage in the behaviour because of how it looked or would be perceived. Social cognitive theory (Luszczynska & Schwarzer, 2005) is also composed of a variety of the elements discussed here. It is useful to be able to see that the theories of behaviour change are reflected in the outcomes of the expert and public interviews, but the real importance of having this information available is that it helped to clearly target the next stages of this research project more appropriately and effectively. Having used the various behaviour change theories to understand some of the drivers behind the performance of protective behaviours the mental models that they have produced also represent areas where behaviour change techniques might be effective. For instance, identification of behavioural barriers was a main output from the interviews. Knowing what stops or discourages people from engaging in a protective behaviour is important in actually forming plans to overcome these barriers. Participants also talked about wanting more information about topics such as the likelihood of coming into contact with an infected tick. This suggests that it might be useful to design communication documents keeping in mind the behaviour change technique of providing information on the link between behaviour and health. In other words, providing people with details of how performing protective behaviours can help minimise their risk of becoming ill.

Conclusions

The interviews with topic experts were useful in determining recommended tick protective behaviours, both primary and secondary, while interviews with members of the public identified a variety of key behavioural drivers and barriers that influence the uptake of each recommended behaviour. These drivers and barriers ranged from non-tick related concerns such as skin allergies and weather conditions to a desire to avoid the disgust associated with tick removal. Interviews with all participants, expert and public, highlighted the more general underlying drivers of all tick protective behaviours including experience, knowledge and risk perceptions. Although the interviews are useful for building a picture or model of tick protective behaviours, they cannot provide any information about how many people practice these behaviours or which behaviours are engaged with more than others. The provision of accurate and clear information forms a key part of the final trial however; rather than using

knowledge as the main outcome measure like much of the existing research, this project will focus on tick checking behaviour as a direct measure of behaviour change. For this information a quantitative survey was conducted, the details and results of which are discussed in the following chapter.

CHAPTER 3: QUANTITATIVE SURVEY

Introduction

The data that were collected from the interviews with topic experts and members of the public (chapter 2) formed the basis of a web survey that was run with members of the public. As well as providing information on the most effective and recommended tick protective behaviours, the interviews, particularly those with the public, delved into the factors that might determine uptake of these behaviours. Participants discussed their knowledge surrounding each protective behaviour as well as the barriers or benefits to practicing different protective behaviours. Interview results suggested that participants had many questions regarding the likelihood of coming into contact with ticks, the likelihood of contracting a tick-borne disease and the possible severity of any such disease, all of which were mentioned as potential drivers of tick-protective behaviour. Participants also spent time talking about tick removal and their concerns about their levels of knowledge and confidence regarding the process. Although the interviews successfully identified particular topics that could be addressed through improved health communications about tick protective behaviours they did not, and were not expected to, provide any details in relation to how prevalent particular behavioural drivers or barriers are or how often people practice protective behaviours. The aim of the survey was to investigate these questions and to quantify the practice of tick protective behaviours so as to provide a baseline from which to measure future behaviour changes. Also, the survey was aimed at being able to understand the relative strength of influence of the behavioural drivers and barriers discussed in the qualitative interviews. For example, the interviews indicated that forgetfulness was one reason why participants reported not engaging in tick checking behaviour; however through use of a survey it is possible to put a number on how many participants report this as a barrier to the behaviour or whether other factors may be of greater importance. Obtaining this more detailed information would make it easier to decide which aspects were priorities for addressing in future communications with the public.

The main outcome variable for the survey was the performance of tick checking behaviour during and after walking or rambling in an area where ticks are present. This was chosen as the main outcome variable because the mental model produced from the topic expert interviews suggested it to be the behaviour that should be most effective at preventing tick-borne disease. Although other protective behaviours are useful, it is still possible to come into contact with ticks and the best way to be aware of their presence on your body is to perform a

tick check. Provided the check is done appropriately and in good time, ticks can be removed before they have the chance to bite, and even if a bite has occurred a good window of opportunity still exists to remove them prior to infection occurring. Bites can also then be monitored and treated where necessary. Three questions were therefore included to assess the prevalence of three tick checking behaviours: performing a tick check focused on clothing while out walking or rambling; performing a tick check of the body while out; and performing a tick check of the body after returning from walking or rambling. These distinctions were made based on information that came from both the topic expert and the public interviews. Experts suggested that checking for ticks every couple of hours while in a tick habitat could be a useful way to quickly spot and remove any ticks that had been encountered. During interviews with members of the public there seemed to be a difference in perception about tick checks and whether they were focused on the body or on the clothes or both. The three questions aimed to understand this potential difference more fully. Secondary outcomes included other behaviours identified in our qualitative interviews as protective, namely: wearing long trousers, wearing light coloured trousers, tucking trousers into socks, sticking to clear pathways, using a repellent on clothes and using a repellent on skin.

On the basis of the results from the qualitative interview, questions were also included on the following topics in order to assess whether they predicted the likelihood of someone checking for ticks: perceived severity of tick-borne disease; perceived likelihood of coming into contact with a tick; perceived likelihood of being bitten by a tick; perceived likelihood of contracting a tick-borne disease; removal confidence and knowledge; perceived control over being bitten; perceived effectiveness of protective behaviours; and level of disgust elicited by ticks.

Finally, the qualitative interviews suggested that certain aspects of knowledge are crucial prerequisites to being able to react appropriately if a tick check reveals the presence of a tick. We therefore also assessed the following: people's ability to recognise a tick and their knowledge of correct tick removal practices.

Methods

Survey design, ethics and procedure

This cross-sectional survey was conducted online using the programme Select Survey. Data collection occurred between 15 March 2012 and 26 May 2012. Having finalised all of the

questions and obtained ethical approval (PNM 11/12-46) the questions were entered into the programme and then tested for any potential errors. When this was complete an email describing the study was sent to potential participants. Participants were told that the survey would involve answering questions about ticks and tick-borne disease in the UK. They were assured that the data would be confidential and anonymous, that participation was voluntary and that they could withdraw from the survey at any point without having to provide a reason. As an incentive to increase participant numbers a draw for a £200 prize was held. If people were interested in participating they were able to click on a web link to the survey which was included in the circular email and then complete the questions. The first survey question informed participants about the confidentiality of any data they provided and required them to indicate that they were happy to continue. In order to take part in the draw participants needed to provide their email address in order to be contactable. Participants who chose to take part in the draw were assured that their email address would be used only in the event that they had won the prize draw and would be kept completely confidential. All email addresses were deleted from the data spreadsheet prior to analysis in order to make the data fully anonymous. The survey was set up so that each participant could only access and complete the survey a maximum of once. It was also necessary for participants to make a response to each question before being able to move forward through the survey. This was done in order to encourage survey completion and to minimise missing data.

Participants

A contact person at the London-based walking group Backabush Xplorers - the same group used to recruit participants for the qualitative interviews described in chapter 2 - agreed to send the survey information and web link to all of the members on their group contact list. In order to increase the number of participants, the recruitment process was also opened up to include any staff or students of King's College London.

In order to participate, respondents had to be at least 18 years of age and fluent in English. In addition, one of the first questions on the survey asked respondents to indicate which of a variety of UK locations they had been to in order to engage in rambling or walking (see appendix 5 for a full list of survey questions). These locations were all areas where ticks are known to be present. If they had not visited any of the locations listed then they were considered ineligible for the study and were automatically redirected to the end of the survey.

Survey questions

Behavioural outcome variable questions

Participants were asked three questions about the primary outcome variable of tick checking behaviour. They were asked whether they checked their clothes for ticks *while* walking, whether they checked their body for ticks *while* walking and whether they checked their body for ticks *after* walking. Possible response options were 'never (coded as a score of 1)', 'almost never (2)', 'about half the time (3)', 'almost always (4)', or 'always (5)'. Those participants who indicated that they either 'never' or 'almost never' performed a tick check of their body after walking or rambling were directed to a question asking why they did not engage in this behaviour. The question consisted of a list of seven potential reasons why someone may not perform a tick check and participants were able to select as many options as were relevant to them. They also had the chance to select 'other' and provide their own reasoning if it had not already been included in the list provided. Participants who reported that after walking or rambling they checked for ticks 'about half the time', 'almost always', or 'always' did not answer the question about reasons for not performing a tick check, but were automatically routed to a question about how they perform their tick check. The question asked participants whether their tick check included particular areas of the body and checking techniques. Again, the possible response options were 'never (coded as a score of 1)', 'almost never (2)', 'about half the time (3)', 'almost always (4)', or 'always (5)'. In case their response was not shown in the available options, participants also had the choice to select 'other' and fill in their own response regarding how they perform a check.

Participants were also asked to indicate how often they performed a series of behaviours "while rambling or walking in any of the UK locations listed above". There were six items, each of which was a protective behaviour that had been identified as an effective tick protective strategy during the interviews with topic experts. The list of behaviours included wearing long trousers, wearing light coloured trousers, tucking trousers into socks, sticking to the clear pathways, using an insect repellent on clothes and using an insect repellent on skin. Response options used the same 'never' to 'always' scale as the previous question. These behaviours were considered as secondary outcomes for this study.

Predictor variable questions

Participants were asked questions concerning perceptions of ticks and tick-borne disease (see appendix 6 for wording). Many of these variables were taken from the revised illness perceptions questionnaire (IPQ-R) (Moss-Morris et al., 2002). Six scales were included to measure different predictor variables. The first scale measured perceived ability to influence or control coming into contact with ticks or tick-borne disease with three items adapted from the IPQ-R personal control subscale. The second scale measured perceived understanding of tick-borne disease through two items that were adapted from the IPQ-R illness coherence subscale. The four remaining scales were created to measure the themes that came out of the public interviews regarding ticks and tick-borne disease. A scale to measure removal confidence asked participants to indicate whether “if a tick bit me I would feel confident about removing it myself” and whether “if a tick bit me I would know how to remove it”. Another scale asked participants about their perceived likelihood of coming into contact with ticks by asking them to agree or disagree with the statements, “I am likely to come into contact with ticks” and “I am likely to be bitten by a tick” if they do not take protective action. A fifth scale measured perceived efficacy of protective behaviours with participants asked to agree or disagree with the statements, “There are effective measures that can prevent people from getting bitten by ticks” and “There is nothing that can be done to prevent people from getting bitten by ticks”. Finally, six items were devised to form the sixth scale which assessed perceptions among participants of ticks as creatures that invoke an emotion or reaction of disgust. These items were based on comments made during the public interviews and were on the physiological symptoms of disgust (Kelly, 2011, p.16). Participants were asked to agree or disagree with the following six statements: “ticks are disgusting”, “having a tick biting me would be disgusting”, “I would be disgusted if I had to remove a tick from myself”, “having a tick biting me would make me feel nauseous”, “I shudder when I think of ticks” and “if I saw a tick near me I would feel a strong instinct to avoid it”.

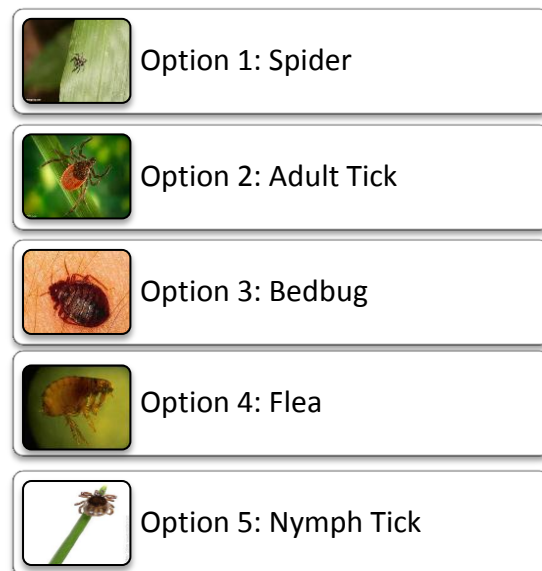
In addition to the above six scales, 10 other items were included to assess a variety of other potential predictor variables such as knowledge of tick habitats, use of precautions when abroad and hassle and forgetfulness. Again, some items were taken from the IPQ-R and some were developed based on the preceding qualitative interviews. These items are all available in appendix 6.

A five-point response format was used for all predictor variables, with participants asked whether they strongly agree (coded as a score of 5), agree (4), neither agree nor disagree (3), disagree (2) or strongly disagree (1) with each statement.

Knowledge and experience

After eligibility for the study had been assessed participants were shown five images and asked to select the ones that they thought were ticks. Figure 3.1 shows these images, together with a description of what they actually represent. Participants were not provided with these descriptions.

Figure 3.1 Tick image identification question options



Participants were told that there may be more than one correct answer and as such they were able to select as many images as they felt appropriate. There were in fact two tick images included in the question, one which showed a tick in the nymph phase of development and one which showed an adult tick: ticks are capable of biting humans at both of those stages of development. The three other images showed a spider, a bedbug and a flea. Participants were then shown the correct answers and were asked whether they had ever experienced a tick bite.

Participants were also asked to indicate which of a series of listed methods could be used to safely remove a tick. Participants had to select any correct options from a list of 7 potential removal strategies. They were allowed to select more than one option if they felt there was

more than one correct answer and were also given the opportunity to write in an additional removal method if they felt that it had not been on the list, but should have been. Possible options were: pull off with tweezers (correct answer), pull off with your fingers (incorrect), cover with Vaseline (incorrect), cover with lighter fluid (incorrect), burn off with a cigarette (incorrect), wait for it to drop off by itself (incorrect), or cover it with salt (incorrect).

Finally, two items tested participants' perceived knowledge by asking them to agree or disagree with the statement, "I know the habitats where I can come into contact with ticks" and "I think there is enough information available about ticks and Lyme disease".

Demographic variables

Participants were asked to give their sex, age, pre-tax household income, highest educational qualification and ethnicity.

Analyses

All analysis was done using IBM SPSS Statistics 19. All incomplete surveys were removed from the dataset prior to analysis. This included surveys which a participant had started but not finished as well as surveys where the participant was found to be ineligible to proceed with the full survey.

Because the majority of participants selected 'never' or 'almost never' for the main outcome variable, this variable was recoded and dichotomised into those who checked 'never (0)' or 'almost never (0)' and those who check 'about half the time (1)', 'almost always (1)' and 'always (1)'.

Any free-text responses relating to safe and effective tick removal strategies were assessed for correctness and coded accordingly. For instance, a participant may have suggested that correct removal should be done with a specific, commercially-available tick removal device. This would have been considered a correct answer.

The first stage of analysis involved assessing the reliability of the predictor variable scales using Cronbach's alphas.

Scores for all predictor variables were tested for normality in order to determine the appropriate parametric or non-parametric analyses. Results from Kolmogorov-Smirnov tests for normality showed that the data for each of the sixteen variables (6 scales and ten stand alone items) were not normally distributed; however several of the variables appeared reasonably normal when viewed as a histogram. For these variables, I ran both Mann-Whitney U tests and independent sample t-tests to assess the association between tick checking behaviour after walking and each predictor variable and determined that there was no change in level of significance. Mann-Whitney U tests were used for the non-normally distributed variables. I calculated odds ratios using logistic regression.

Chi-square tests for independence were run on all of the demographic variables and the main outcome variable of performing a tick check after walking. None of these variables showed any association to the performance of a tick check. Given this, I did not adjust for demographics when testing the association of the psychological variables with the outcome variable.

Recoding was used to simplify the analysis of the demographic variables including ethnicity, education and income. Ethnicity was recoded as 'white' or 'any other ethnic background', education was recoded as 'anything up to and including A-levels or equivalent' or 'Bachelor degree or equivalent or higher'. Finally, income was recoded as '< £10,000 to £30,000', '£30,000 to £50,000', '£50,000 or over' or 'don't know / prefer not to say'.

Results

Sample

By 18 April 2012 there had been 101 responses from members of the Backabush Xplorers walking group. In order to increase participant numbers and gain a larger sample it was decided at this stage to open the survey up to the staff and students of King's College London. After sending the survey details out to all King's College London staff and students by email the number of responses rose to a total of 488. After the exclusion of all 145 incomplete or ineligible surveys there were a total of 343 participants who provided a full set of responses.

Participant demographics

274 participants (72%) were female. All participants were between the ages of 18 and 67, with 65% aged 34 or younger. The median age was 40.5.

Participant household income was fairly evenly distributed across the income categories. Apart from the 4% of participants who reported not knowing their annual household income, the remaining income categories had participant response rates of between 9% and 14%.

The majority of participants reported their highest educational qualifications as either a bachelor degree or equivalent (36% of participants), or a masters or PhD (45% of participants).

The vast majority of participants indicated that they were either 'White-British' (64%), 'White-Irish' (2%), or 'White-Any other background' (23%). Answers were therefore recoded either as 'White', 'Any other background' and 'Prefer not to answer'. See table 3.1 for full demographic details.

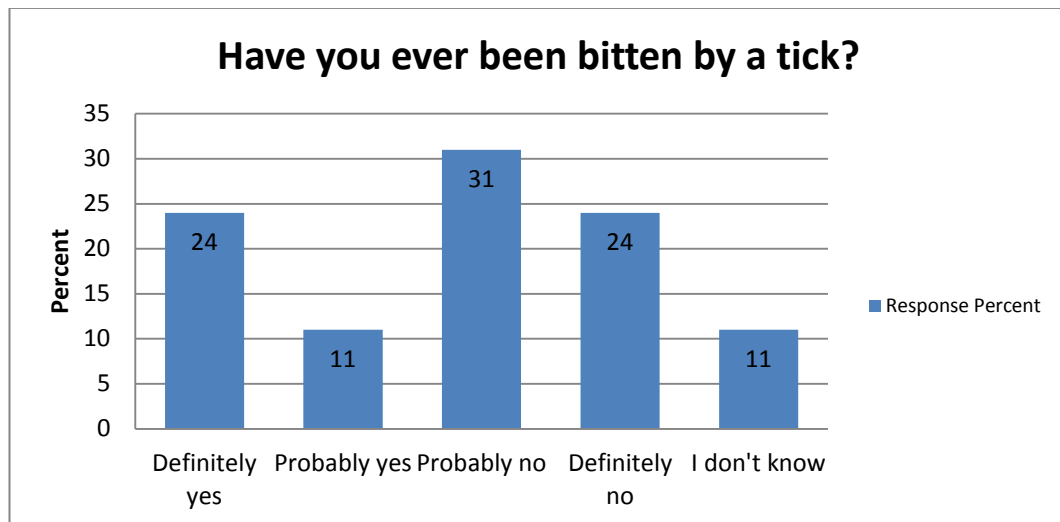
Table 3.1 Participant demographics (data from 343 participants)

Demographic Variable	Response (%)
Gender	
Male	97 (28%)
Female	246 (72%)
Age	
18-24	92 (27%)
25-34	132 (38%)
35-44	57 (17%)
45-54	44 (13%)
55+	18 (5%)
Income	
Under £10,000	47 (14%)
Over £10,000 but less than £20,000	33 (10%)
Over £20,000 but less than £30,000	39 (11%)
Over £30,000 but less than £40,000	42 (12%)
Over £40,000 but less than £50,000	39 (11%)
Over £50,000 but less than £75,000	58 (17%)
Over £75,000	39 (11%)
Don't know	14 (4%)
Prefer not to say	32 (9%)
Education	
GCSE / O-level / CSE	6 (2%)
Vocational qualifications (=NVQ1+2)	3 (1%)
A-level or equivalent (=NVQ3)	33 (10%)
Bachelor Degree or equivalent (=NVQ4)	124 (36%)
Masters / PhD or equivalent	154 (45%)
Other	3 (1%)
No formal qualifications	1 (0%)
Still studying	19 (6%)
Don't know	0 (0%)
Ethnicity	
White (British, Irish, any other white background)	305 (89%)
Any other ethnicity*	31 (9%)
Prefer not to say	7 (2%)

*includes the following ethnicity categories: Asian or Asian British - Indian, Pakistani, Bangladeshi, Any other Asian background; Black or Black British – Caribbean, African, Any other Black background; Mixed – White and Black Caribbean, White and Black African, White and Asian, Any other mixed background; Chinese or other ethnic group – Chinese, Any other background

Fifty-five percent of participants reported that they had either probably not been bitten, or had definitely not been bitten, with 35% saying they had definitely, or probably been bitten. The full breakdown of participant bite experience can be seen in figure 3.2.

Figure 3.2 Based on data from 352 respondents.



Behavioural reactions: primary outcomes

The majority of participants indicated that they 'never' or 'almost never' checked for ticks. 265 participants (76%) reported 'never' or 'almost never' performing a tick check after walking, while only 20 participants (6%) 'always' checked for ticks after walking. Participants rarely checked their clothes for ticks while walking, with only 52 participants (15%) checking 'always', 'almost always' or 'about half the time'. Results were similar for tick checking of the body while walking with only 48 participants (14%) checking 'always', 'almost always', or 'about half the time'. Figures 3.3, 3.4 and 3.5 provide a more detailed breakdown of tick check behaviour response rates.

Figure 3.3 Based on data from 346 respondents.

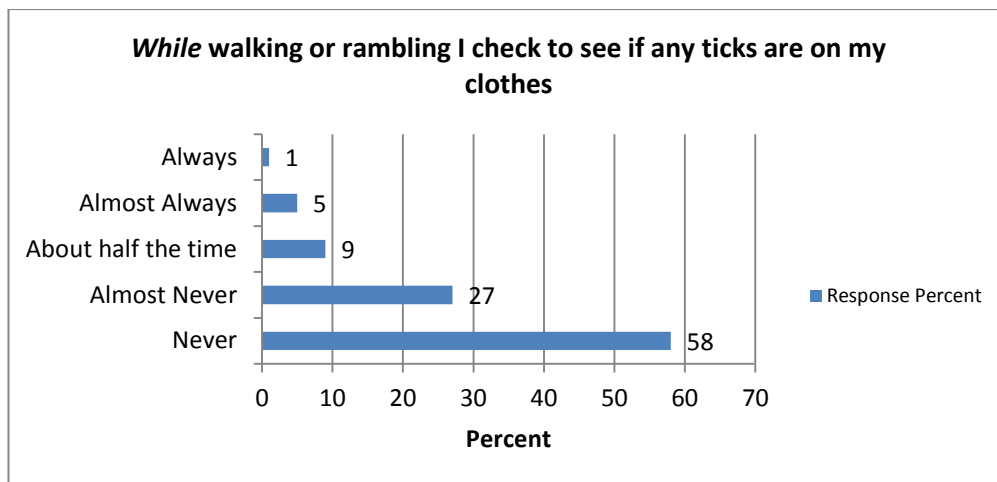


Figure 3.4 Based on data from 345 respondents.

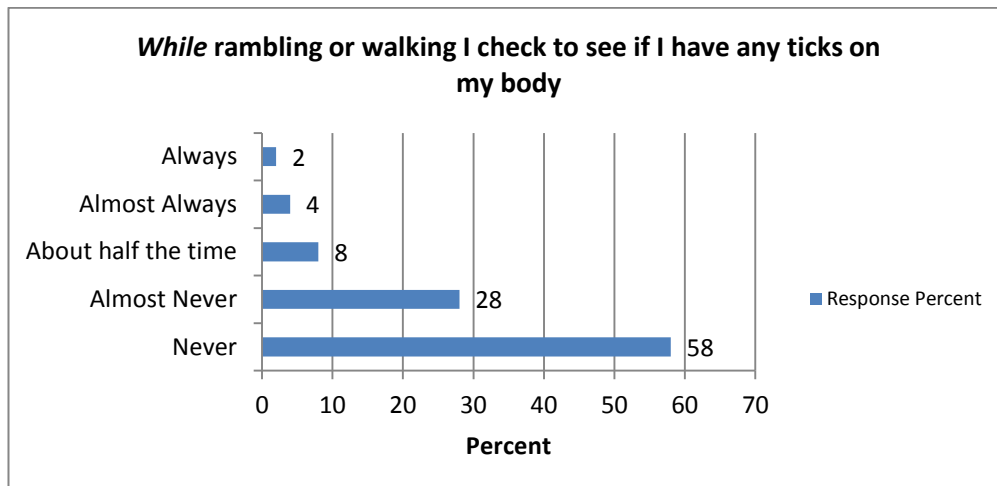
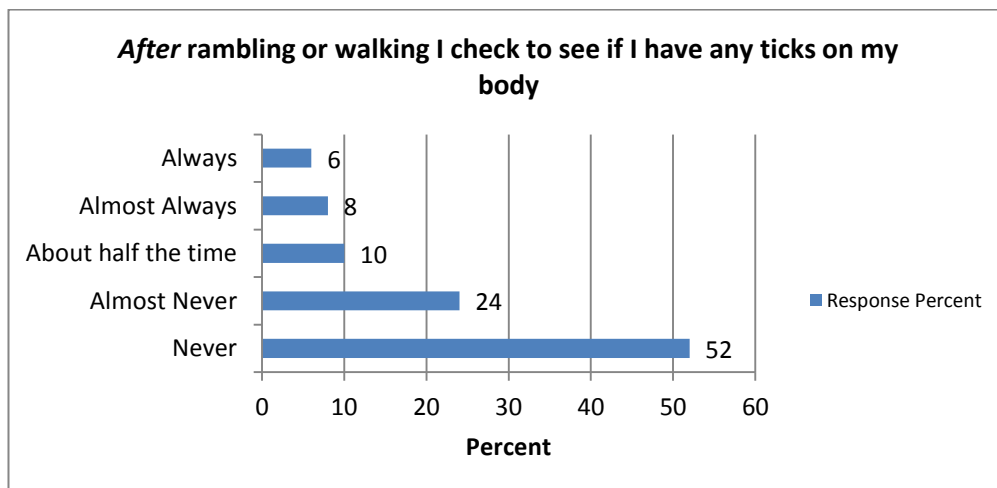
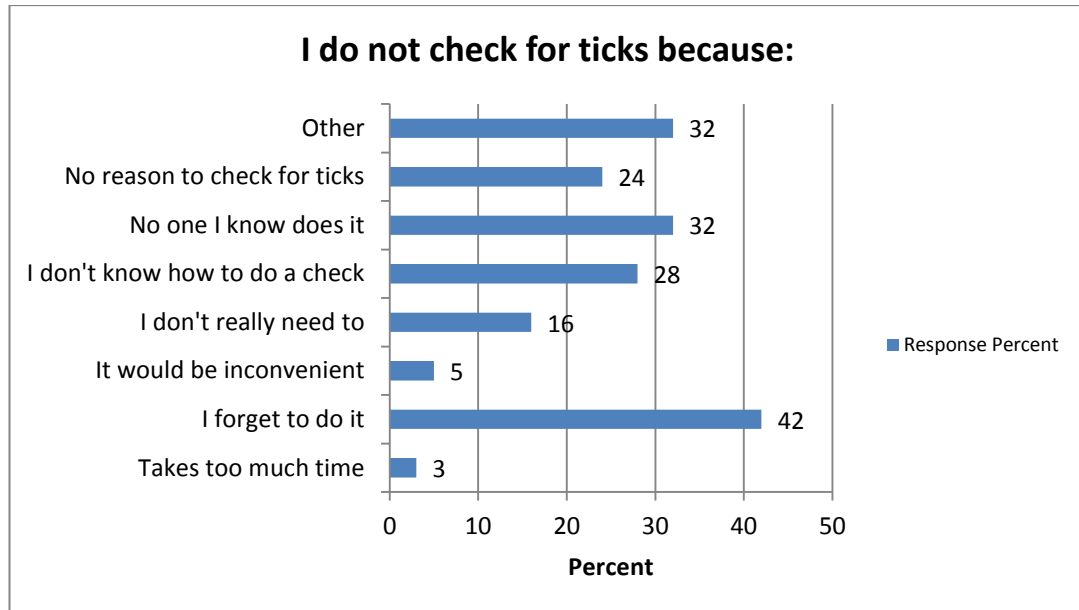


Figure 3.5 Based on data from 346 respondents.



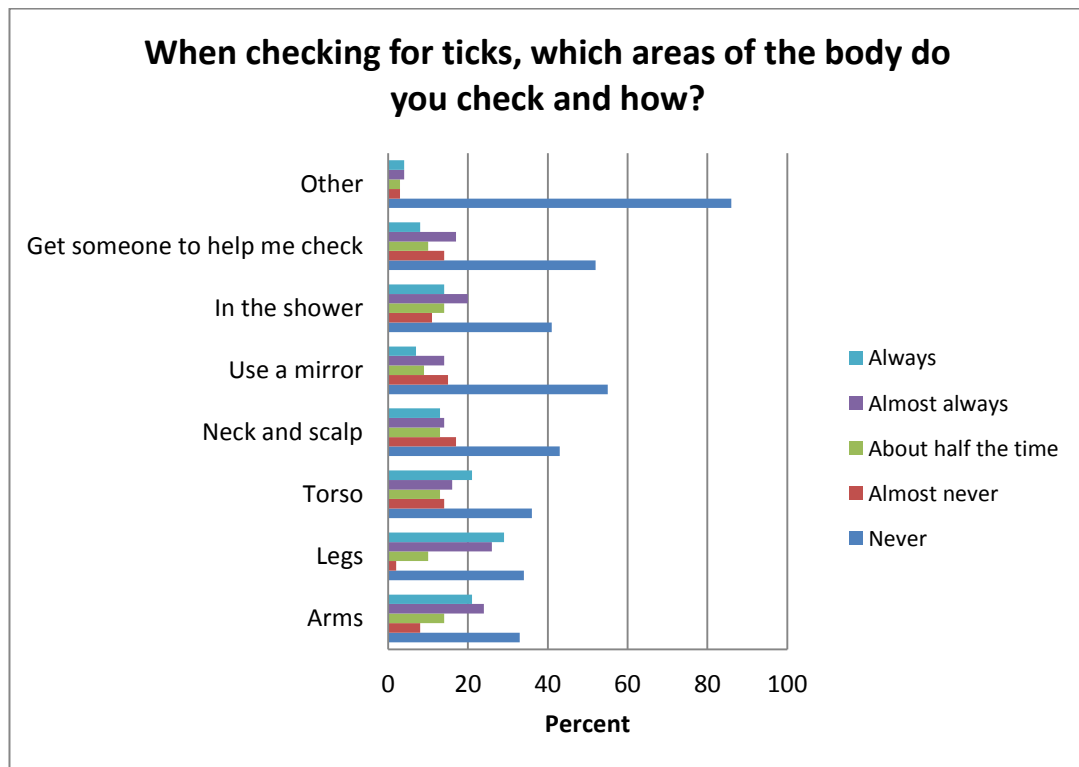
'Forgetting' was most frequently reported as the reason for failing to perform a tick check after walking, with 111 participants (42%) reporting this. Not knowing someone who performs a check (n=86, 32%) and 'other' (n=84, 32%) were also commonly endorsed by participants. When the free-text 'other' responses were reviewed, the most common answer that had been brought up was being unaware that a tick check was necessary or that ticks existed in the UK (n=43, 16%). The results for all reasons are shown in figure 3.6.

Figure 3.6 Based on data from 265 respondents.



The full breakdown of how and which parts of their body respondents checked for ticks can be seen in figure 3.7. The most commonly checked areas of the body reported by participants included the legs and arms, each with over 40% of participants saying that they check the area ‘always’ or ‘almost always’.

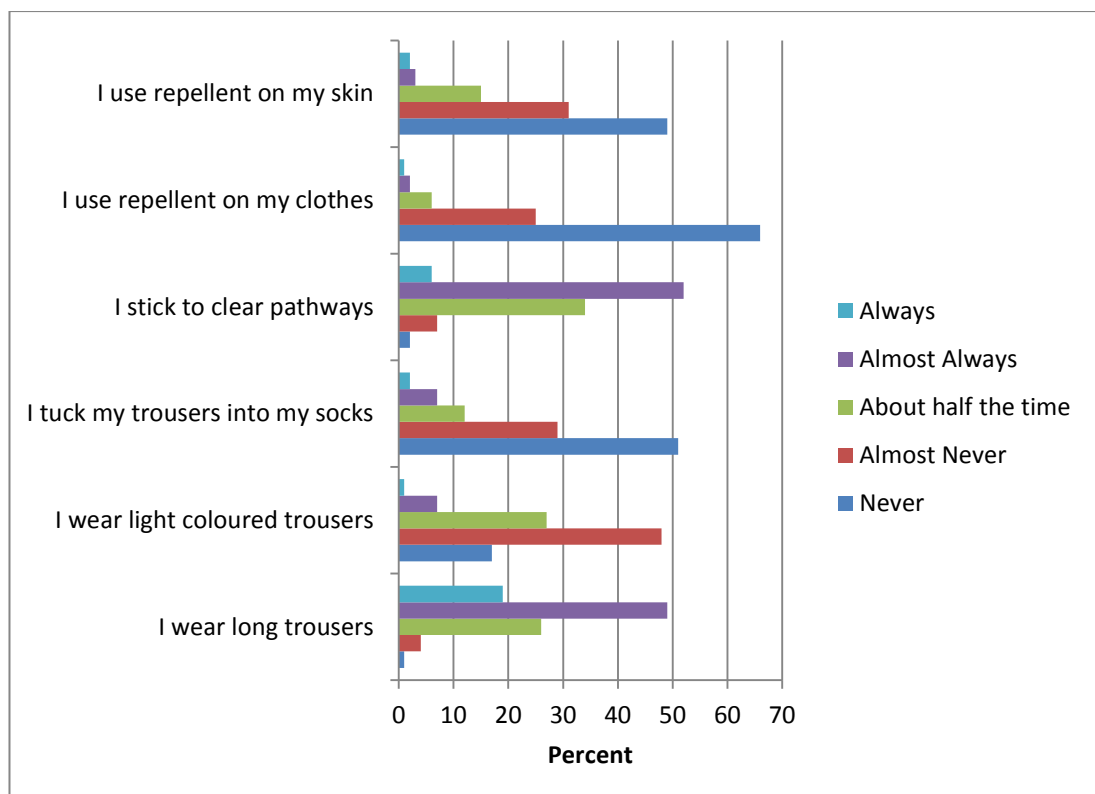
Figure 3.7 Based on data from 133 respondents



Behavioural reactions: secondary outcomes

The majority of participants (68%) reported wearing long trousers ‘almost always’ or ‘always’ when they went walking or rambling, however 65% of participants said these trousers are ‘almost never’ or ‘never’ light coloured. Furthermore, only 9% of participants reported tucking their trousers into their socks ‘almost always’ or ‘always’. Sticking to cleared pathways when walking or rambling had a higher rate of success with 85% of participants indicating that they did this ‘about half the time’ or ‘almost always’. The use of a repellent was largely unpopular either on clothing or skin with usage of ‘about half the time’, ‘almost always’ or ‘always’ being at 6%, 2% and 2% respectively for clothing and 15%, 3% and 2% respectively for skin. A full breakdown of scores for each tick protective behaviour is given in figure 3.8.

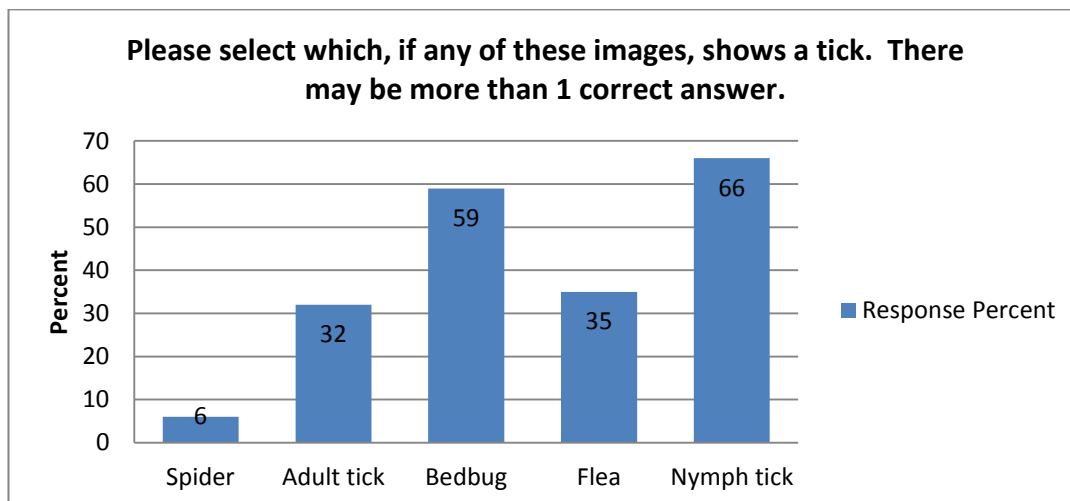
Figure 3.8 Please indicate how often you do each of the following while rambling or walking in any of the UK locations listed above. Based on data from 346 respondents.



Background knowledge

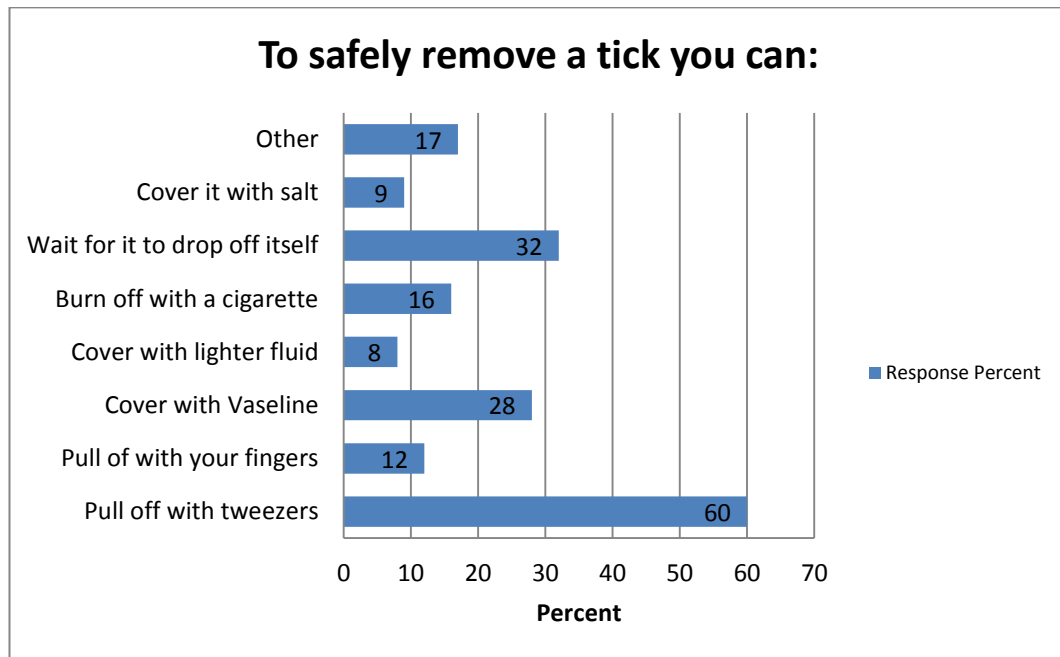
A nymph tick was chosen as a tick image by 238 participants (66%) compared to the adult tick which was selected only 115 participants (32%). Only 51 participants (15%) correctly identified both images, while 252 (74%) got no images correct and 40 (11%) chose only one correct image (see figures 3.9).

Figure 3.9 Based on data from 358 respondents.



When asked to select safe tick removal strategies from a list of 8 possible options, the correct response of removal with tweezers was the most selected strategy by 212 participants (60%). Other popular responses included waiting for the tick to drop off by itself (32%) and covering the tick with Vaseline (28%). The full breakdown of responses by removal strategy is available in figure 3.10.

Figure 3.10 Based on data from 352 respondents.



Because participants were able to select as many tick removal strategies as they deemed appropriate, it was possible for someone who had selected the correct option to also select an incorrect option. The overall response of that participant was then considered to be incorrect. Only 30% of participants selected the correct answer and no incorrect answer.

Association between demographic variables and outcomes

No significant associations were found between any demographic variables and the primary outcome variable of performing a tick check at least half the time after walking in tick-affected area (see table 3.2). There were also no significant associations between any of the demographic variables and the secondary outcome variables of checking clothes for ticks while walking or checking your body for ticks while walking. Similarly, no significant associations were found between any of the demographic variables and the secondary outcome variables of sticking to clear pathways when walking, use of repellent on clothes when walking or use of repellent on skin when walking (see appendices 7 to 14 for all details of associations).

Significant associations were found between ethnicity and wearing long trousers when walking; gender and age and wearing light coloured trousers when walking; and gender and tucking trousers into socks when walking. Logistic regressions were performed to assess the impact of these factors on the likelihood of performing each of the outcome variables. Each model contained five independent variables (gender, age, income, qualifications and ethnicity). The first model found that the strongest predictor of reporting wearing long trousers on at least half of the occasions when out walking was ethnicity, with an odds ratio of 4.86 (CI 95% 1.6 to 14.5). This indicated that respondents of White ethnicity were 4 times more likely to report wearing long trousers when out walking, controlling for all other factors in the model. The second model found that the strongest predictors of wearing light coloured trousers at least half the time when out walking were gender and age, with odds ratios of 1.92 (CI 95% 1.2 to 3.2) and 1.26 (CI 95% 1.0 to 1.6) respectively, indicating that older and male respondents were more likely to report wearing light coloured trousers. Finally, the third logistic model found that the strongest predictor of tucking trousers into socks at least half the time when walking was gender, with an odds ratio of 0.47 (CI 95% 0.2 to 0.9). This indicated that male participants were less likely to report tucking their trousers into their socks when out walking, all other factors being equal.

Table 3.2 Associations between demographic variables and tick checking behaviour.

Demographic Variable	No (%) of participants	No (%) performing tick check at least half the time after walking	χ^2	p
Gender			0.06	0.81
Male	97 (28.0)	21 (21.6)		
Female	246 (72.0)	58 (23.6)		
Age			2.33	0.68
18-24	92 (27.0)	23 (25.0)		
25-34	132 (38.0)	31 (23.5)		
35-44	57 (17.0)	11 (19.3)		
45-54	44 (13.0)	8 (18.2)		
55+	18 (5.0)	6 (33.3)		
Income			0.66	0.88
<10,000 - £30,000	119 (34.7)	29 (24.4)		
Over £30,000 but less than £50,000	81 (23.6)	17 (21.0)		
Over £50,000	97 (28.3)	20 (20.6)		
Don't know / prefer not to say	32 (9.3)	8 (25.0)		
Qualifications			0.02	0.88
GCSE / vocational / A-level / still studying / other	65 (19.0)	14 (21.5)		
Bachelor degree / Masters / PhD	278 (81.0)	65 (23.4)		
Ethnicity			1.45	0.23
White (British, Irish, any other white background)	305 (89.0)	74 (24.3)		
Any other ethnicity*	31 (9.0)	4 (12.9)		
Prefer not to say	7 (2.0)	1 (14.3)		

*includes the following ethnicity categories: Asian or Asian British - Indian, Pakistani, Bangladeshi, Any other Asian background; Black or Black British – Caribbean, African, Any other Black background; Mixed – White and Black Caribbean, White and Black African, White and Asian, Any other mixed background; Chinese or other ethnic group – Chinese, Any other background

Association between psychological variables and outcomes

The Cronbach's alphas for the six scales (see table 3.3) ranged from good ($\alpha=0.70$) to excellent ($\alpha=0.92$).

Table 3.3 Predictor scales reliability

Predictor scales, with examples of items	Cronbach's α
<i>Knowledge (2 items)</i>	
I don't understand Lyme disease	0.92
<i>Disgust (6 items)</i>	
Ticks are disgusting	0.87
<i>Likelihood (2 items)</i>	
I am likely to come into contact with ticks when out walking	0.87
<i>Removal confidence (2 items)</i>	
If a tick bit me I would know how to remove it	0.85
<i>Efficacy (2 items)</i>	
There are effective measures that can prevent people from getting bitten by ticks	0.74
<i>Control (3 items)</i>	
Whether or not I get bitten by a tick when out walking would depend on me	0.70

Mean scores for each of the psychological predictor variables are shown in table 3.4. This table also shows the association between the psychological variables and tick checking behaviour after walking.

Table 3.4 Logistic regression predicting tick checking behaviour after walking

Predictor Variable (example statement)	Mean (SD) score ^a , No of participants	p	Odds ratio (95% CI) for tick checking after walking
Disgust (Ticks are disgusting)	3.16 (0.87), 343	0.003	0.64 (0.48 to 0.87)
Efficacy (Nothing can be done to prevent people getting bitten by ticks)	3.85 (0.64), 343	0.02	1.66 (1.10 to 2.54)
Control (Whether or not I get bitten would depend on me)	3.47 (0.70), 343	0.10	1.36 (0.94 to 1.98)
Getting bitten would have serious consequences on my life	2.91 (0.90), 343	0.86	0.98 (0.75 to 1.27)
What I do could determine whether or not I came into contact with ticks	3.51 (1.03), 343	0.0005	1.64 (1.23 to 2.19)
Checking for ticks is too time consuming	2.61 (0.90), 343	0.0005	0.46 (0.33 to 0.65)
Tick bites can be effectively treated	3.76 (0.73), 343	0.95	0.99 (0.70 to 1.40)
If I was bitten by a tick I would get Lyme disease	2.67 (0.68), 343	0.01	0.62 (0.43 to 0.91)
There is enough information available about ticks and Lyme disease	2.27 (1.00), 343	0.0005	1.68 (1.31 to 2.16)
Removal confidence (If a tick bit me I would know how to remove it)	2.87 (1.15), 343	0.0005	2.13 (1.64 to 2.75)
Likelihood (I am likely to be bitten by a tick)	2.85 (0.87), 343	0.0005	1.78 (1.32 to 2.41)
Knowledge (I don't understand Lyme disease)	2.43 (1.04), 343	0.0005	2.44 (1.86 to 3.19)
I would normally forget to check for ticks	3.74 (1.11), 343	0.0005	0.32 (0.24 to 0.42)
I know tick habitats	2.57 (1.21), 343	0.0005	2.95 (2.22 to 3.92)
I take precautions against ticks when I'm abroad	2.49 (1.17), 343	0.0005	1.97 (1.57 to 2.48)
Lyme disease is a serious condition	4.28 (0.75), 343	0.001	1.87 (1.27 to 2.75)

^aScores range from 1 (strongly disagree) to 5 (strongly agree)

People were more likely to engage in tick checking behaviour if they: found ticks less disgusting, had higher confidence about removal, perceived the likelihood of being bitten as greater and had greater perceived knowledge about ticks. People were also more likely to engage in checking behaviour if they believed their behaviour could determine contact with ticks, if they felt enough information was available about ticks and Lyme, if they reported checking for ticks when abroad, if they felt Lyme is a serious condition, if they thought being bitten by a tick would result in Lyme and if they knew where tick habitats were. People were less likely to perform tick checking behaviour if they reported checking for ticks to be too time consuming and if they reported normally forgetting to check for ticks. The remaining three variables were not significantly associated with the performance of tick checking behaviour.

The results remained the same for tick checking of the body while walking (see table 3.5), but showed some slight differences for tick checking of the clothes while walking.

Table 3.5 Logistic regression predicting tick checking of the body while walking^aScores range from 1 (strongly disagree) to 5 (strongly agree)

Predictor Variable (example statement)	Mean (SD) score ^a , No of participants	p	Odds ratio (95% CI) for tick checking body while walking
Disgust (Ticks are disgusting)	3.16 (0.87), 343	0.003	0.57 (0.39 to 0.83)
Efficacy (Nothing can be done to prevent people getting bitten by ticks)	3.85 (0.64), 343	0.03	1.82 (1.07 to 3.09)
Control (Whether or not I get bitten would depend on me)	3.47 (0.70), 343	0.17	1.38 (0.87 to 2.20)
Getting bitten would have serious consequences on my life	2.91 (0.90), 343	0.61	1.09 (0.79 to 1.51)
What I do could determine whether or not I came into contact with ticks	3.51 (1.03), 343	0.008	1.62 (1.13 to 2.33)
Checking for ticks is too time consuming	2.61 (0.90), 343	0.001	0.52 (0.35 to 0.77)
Tick bites can be effectively treated	3.76 (0.73), 343	0.18	0.76 (0.50 to 1.14)
If I was bitten by a tick I would get Lyme disease	2.67 (0.68), 343	0.021	0.58 (0.36 to 0.92)
There is enough information available about ticks and Lyme disease	2.27 (1.00), 343	0.0005	1.73 (1.28 to 2.33)
Removal confidence (If a tick bit me I would know how to remove it)	2.87 (1.15), 343	0.0005	1.93 (1.43 to 2.65)
Likelihood (I am likely to be bitten by a tick)	2.85 (0.87), 343	0.003	1.73 (1.20 to 2.49)
Knowledge (I don't understand Lyme disease)	2.43 (1.04), 343	0.0005	2.16 (1.58 to 2.94)
I would normally forget to check for ticks	3.74 (1.11), 343	0.0005	0.32 (0.24 to 0.44)
I know tick habitats	2.57 (1.21), 343	0.0005	2.84 (2.00 to 4.03)
I take precautions against ticks when I'm abroad	2.49 (1.17), 343	0.0005	2.01 (1.53 to 2.66)
Lyme disease is a serious condition	4.28 (0.75), 343	0.012	1.87 (1.15 to 3.05)

Disgust, perceived likelihood and Lyme as a serious condition were no longer significantly associated with this predictor variable, but results remained otherwise identical (see table 3.6).

Table 3.6 Logistic regression predicting tick checking of the clothes while walking

Predictor Variable (example statement)	Mean (SD) score ^a , No of participants	p	Odds ratio (95% CI) for tick checking clothes while walking
Disgust (Ticks are disgusting)	3.16 (0.87), 343	0.13	0.76 (0.54 to 1.08)
Efficacy (Nothing can be done to prevent people getting bitten by ticks)	3.85 (0.64), 343	0.009	2.01 (1.19 to 3.39)
Control (Whether or not I get bitten would depend on me)	3.47 (0.70), 343	0.46	1.18 (0.76 to 1.83)
Getting bitten would have serious consequences on my life	2.91 (0.90), 343	0.98	0.99 (0.73 to 1.36)
What I do could determine whether or not I came into contact with ticks	3.51 (1.03), 343	0.007	1.61 (1.14 to 2.28)
Checking for ticks is too time consuming	2.61 (0.90), 343	0.0005	0.47 (0.32 to 0.70)
Tick bites can be effectively treated	3.76 (0.73), 343	0.13	0.73 (0.49 to 1.10)
If I was bitten by a tick I would get Lyme disease	2.67 (0.68), 343	0.01	0.55 (0.35 to 0.87)
There is enough information available about ticks and Lyme disease	2.27 (1.00), 343	0.0005	1.82 (1.36 to 2.44)
Removal confidence (If a tick bit me I would know how to remove it)	2.87 (1.15), 343	0.0005	1.83 (1.37 to 2.45)
Likelihood (I am likely to be bitten by a tick)	2.85 (0.87), 343	0.062	1.39 (0.98 to 1.96)
Knowledge (I don't understand Lyme disease)	2.43 (1.04), 343	0.0005	2.11 (1.57 to 2.85)
I would normally forget to check for ticks	3.74 (1.11), 343	0.0005	0.40 (0.30 to 0.53)
I know tick habitats	2.57 (1.21), 343	0.0005	2.68 (1.93 to 3.72)
I take precautions against ticks when I'm abroad	2.49 (1.17), 343	0.0005	1.76 (1.36 to 2.28)
Lyme disease is a serious condition	4.28 (0.75), 343	0.103	1.44 (0.93 to 2.22)

^aScores range from 1 (strongly disagree) to 5 (strongly agree)

Associations were also analysed between each of the secondary outcome variables and the predictor variables. This showed that participants were more likely to report wearing long trousers when walking if they had greater knowledge about ticks and if they knew tick habitats. Participants were more likely to report wearing light coloured trousers when walking

if they had lower levels of disgust, if they felt they could control their contact with ticks, if they perceived the likelihood of being bitten as greater, if they knew tick habitats and if they viewed Lyme disease as a serious condition. Trousers were more likely to be tucked into socks when walking if participants felt tick bites could not be effectively treated, if they thought they would forget to check for ticks, if they knew tick habitats and if they reported taking precautions against ticks when abroad. Participants were more likely to stick to clear pathways when walking if they perceived that being bitten by a tick would result in Lyme disease. The use of repellent on clothes when walking was associated with higher levels of efficacy, finding tick checking too time consuming or something which would be forgotten, having higher levels of removal confidence, having greater knowledge about ticks and tick habitats and engaging in precautions against ticks when abroad. Finally, the use of repellent on skin while walking was greater among participants who reported tick checking to be too time consuming, who would forget to check for ticks and who take precautions against ticks with abroad. Any predictor variables not mentioned with these outcome variables is due to a non-significant association. Full details of all results for each outcome variable can be found in Appendices 15 through 20.

Discussion

Links to theory and previous studies

This survey has shown that the study population of people who live in London but who are at risk of coming into contact with ticks and tick-borne disease through engagement in outdoor activities often fail to check themselves for ticks after walking or rambling in an affected area. Even when a tick check is performed it is often done incorrectly, with many participants failing to accurately identify a tick, check all parts of their body, and use a mirror for hard to see places or perform a check in the shower.

In addition to the uncertainty surrounding the performance of tick checking behaviour, the results of the survey also highlighted a lack of awareness and clarity regarding safe tick removal options. The correct removal method was selected by the majority of survey participants; however many participants also selected another, incorrect, option. When this had been accounted for only 30% of participants gave a fully correct answer, indicating that while the majority of participants knew an appropriate removal technique, they were unsure

about the safety or effectiveness of other techniques. This confusion about appropriate tick removal was initially identified during the interviews with members of the public where knowledge about removal appeared to be lacking. Participants reported that they felt there were mixed messages available about how to safely remove a tick. In the past there have been suggestions that ticks could be removed by doing things such as smothering them with Vaseline or lighter fluid, by burning them off with a cigarette, or by pulling the tick off with your fingers. More recent public information has attempted to address these myths by highlighting the correct removal process and by explicitly stating how not to remove a tick as shown by the downloadable leaflet available on the Public Health England website (http://www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1194947317401). Although it is good to challenge and address these myths or misunderstandings, research has shown that simply providing educational measures to correct misconceptions could potentially do more harm than good (Nyhan, Brendan, & Reifler, 2010): repeating misinformation in an attempt to discredit it can actually enhance its perceived truth. Given that tick-borne disease is on the increase in the UK these findings highlight the need for interventions aimed at improving tick checking behaviours.

The results suggest several factors that could usefully be included in any such intervention. The most interesting finding was that although the disgust data came out as significantly associated with tick checking, it was not necessarily in the direction that might be expected. After conducting interviews with members of the public as described in chapter 2, disgust had been identified as a potential driver of the practice of tick protective behaviours. I was expecting to find that feelings of disgust towards ticks would conform to the theory of a behavioural immune system as discussed in chapter 1. In this theory it is suggested that the emotional state of disgust can act as a motivator or driver of behavioural avoidance (Schaller & Park, 2011). Based on this, it was thought that feelings of disgust might result in people wanting to avoid ticks and therefore engaging in more protective behaviours. However, the survey results have shown that the relationship between disgust and protective behaviours is slightly more nuanced than this and that participants who reported higher levels of disgust towards ticks were significantly less likely to engage in the main outcome variable of performing a tick check after walking. It remains unclear why this is the case; however it is possible that this finding does indeed relate to avoidance, defined rather more broadly. Rather than disgust driving people to practice protective behaviours so as to avoid coming into contact with ticks, it seems that people do not check for ticks because they may be keen to

avoid having to deal with any potential negative emotions such as disgust if they were to find a tick on themselves. This avoidant reaction is supported by research into 'experiential avoidance,' whereby an individual attempts to avoid experiences that lead to thoughts, emotions or sensations that they find unpleasant, even if this avoidance ultimately creates more harm in the longer term (Hayes, Wilson, Gifford, Follette, & Strosahl, 1996). This experiential avoidance is then negatively reinforced by reducing feelings of discomfort in the short term (Sloan, 2004). In this case, participants with higher self reported levels of disgust seem to be avoiding the practice of tick checking behaviour after walking as a way to avoid the discomfort caused by emotions of disgust if they were to find a tick on their body.

Theories of behaviour change such as Protection Motivation Theory and the Health Belief Model may also be useful to understand the predictors of protective behaviour identified by this survey (Rogers, 1975; Cameron, 2009). According to these theories, threat appraisal formation is based on perceptions of the likelihood of an event occurring and the severity of the event (Rogers, 1975). In this case the event is the experience of being bitten by a tick and potentially contracting a tick-borne disease such as Lyme disease. As with the interviews, the survey indicated that levels of awareness and knowledge regarding these topics was low among participants and these risk perceptions were identified as drivers influencing the uptake of tick protective behaviour. Given the low levels of awareness, perhaps it is possible that if participants were provided with information to address these risk perceptions they would then form altered threat appraisals. Similarly, the formation of a coping appraisal is based upon an individual's perceptions about the response efficacy of and self efficacy for a particular behaviour, in this case performing a tick check (Cameron, 2009). Previous studies of tick-borne disease prevention behaviours have found that perceived severity of disease and high levels of self-efficacy were predictors of precautionary behaviour performance (Daltroy et al., 2007). Results of this survey are consistent with these findings. Previous studies have also found that higher levels of concern about being bitten by ticks are associated with taking preventive measures (Herrington, 2004). A similar association was found with this survey as data showed that those who perceived the likelihood of being bitten by a tick as greater and who felt that being bitten by a tick would result in Lyme disease were more likely to engage in tick checking behaviours. Previous studies have not looked at tick checking behaviour specifically so it is possible that some difference could exist. Results have shown that there is confusion surrounding what a tick check is and how to perform it effectively. This survey revealed that even amongst participants who reported performing a tick check at least 'about half the time'

after having been out walking there were still low reported rates of checking each area of the body. Participants expressed a lack of knowledge about tick checks, particularly in terms of the knowledge that such a thing existed as well as knowledge about how to correctly perform the behaviour. As with the threat appraisals, clearly these uncertainties will have influenced the coping appraisals formed by participants and ultimately their tick protective behaviour practices. It is unrealistic to expect people who are unaware of the existence of a tick check to engage in such behaviour.

Three of the psychological predictor variables failed to show any significant association with the performance of tick checking behaviour. Surprisingly, one of these variables was control, which was measured using a scale composed of three items to assess perceptions of personal control regarding tick bites and tick-borne disease. I had anticipated that participants who reported performing tick checks might be people who also reported higher levels of control. It is difficult to explain this lack of association, however previous research into control as a predictor of health related behaviour has produced mixed findings (Walker, 2001; Norman et al., 1998).

Engaging in tick checking behaviour also showed a lack of association with the variables, “Getting bitten by a tick would have serious consequences on my life” and “Tick bites can be effectively treated”. This could be due to the fact that both of these variables were influenced by the fact that knowledge about ticks and tick-borne disease was low among the majority of participants meaning that it was difficult for participants to answer these questions.

Methodological limitations

Participants were initially recruited from walking or rambling organisations based in London, but to increase the number of responses emails were sent to King’s College London staff and students inviting them to take part in the survey. This had the desired effect of bolstering recruitment; however when looking at the demographic results it is obvious that the majority of participants were university students. Specifically, participants in this study tended to be young, affluent, well-educated and White. This means that generalisability to other demographic groups could be difficult. However despite this the participants all met the inclusion criteria of living in London and having been walking or rambling in at least one of the specified UK locations. Generalisability is also limited by the greater female response to the survey. More women than men took part in the study; in fact 72% of respondents were

female versus 28% who were male. Previous studies looking at response rates to web versus paper surveys have found mixed results in terms of gender responses with some suggesting that males are more likely to respond in an online setting (Smith & Leigh, 1997) and others providing evidence to the contrary (Sax, Gilmartin, & Bryant, 2003).

Although web surveys offer a number of benefits, particularly in terms of time, cost and participant convenience, they do have two potential drawbacks. Firstly, all potential participants may not have equal access to the internet. A 2011 study by the European Commission found that household internet access in the UK continues to increase from a rate of 67% in 2007 to 85% in 2011 (Seybert, 2011). Findings also showed that within the EU, nine in ten individuals aged 16-24 used the internet regularly, as did nine in ten higher educated individuals. Given these statistics, it seems unlikely that there was much unequal access to the internet among survey participants. Furthermore, all university staff and students were invited to participate in the study through their university issued email address and would have had access to the internet at the university even if it was not available in their home, while the BackaBush group is a primarily web-based organisation. Secondly, it may also be possible that some potential survey participants decided against taking part in the study because of concerns over data safety and confidentiality online. To counter this concern it was made clear to participants that the entire process had been granted ethical approval by the university and was compliant with the Data Protection Act 1998.

Social desirability is another potential limitation to this survey as participants may have responded in the manner that they thought would be preferred in order to appear responsible. For example, a participant may have reported tick checking behaviour after walking even if they do not actually engage in this behaviour. If this was the case, then the results would be an overestimation of the proportion of people who currently engage in tick checking behaviour. Even if some participants were providing false information about tick checking behaviour the uptake was still found to be very low suggesting that the real situation is likely to be even worse.

Finally, it is also possible that non-response bias could pose a limitation to the interpretation of the survey results. There could potentially be differences that exist between people who have chosen to take part in this survey about ticks and tick-borne disease and those who do not. For instance, people who have come into contact with ticks previously or who have been

bitten by a tick may have more interest in completing the survey than those without any prior knowledge or experience of the topic. In this case the results would overestimate awareness and knowledge of ticks.

Implications for communication

The results from the survey have a number of implications for the design of communication interventions. Firstly, it is obvious that the public requires increased awareness about ticks and tick-borne disease. This means that communication materials should include information about what ticks are, with the inclusion of images to help people identify what a tick looks like and to prepare them for how small a tick can be. Secondly, the public need to be told about what a tick check is, when to perform one and how to effectively perform one. Thirdly, people need to be provided with clear information about how to safely and effectively remove a tick. In particular there appears to be a role for both self and response efficacy to play with regards to the promotion of tick checking behaviour. People need to feel confident in their own ability to effectively perform a behaviour, but they also need to be confident that the behaviour itself will be effective. These are topics that should be addressed in communication materials. Fourthly, a number of barriers to tick preventive behaviour were identified. Among the most important was the finding that forgetfulness is one of the major reasons for not performing a tick check. This suggests that communication materials need to be designed to specifically address these barriers in order to garner greater changes in behaviour. Finally, the data from this survey suggest that one way of potentially seeing an increase in the practice of tick checking behaviour could be to reduce feelings of disgust regarding ticks among the public. Each of these points will be taken into consideration during the intervention design stage of the following pilot randomised controlled trial.

Conclusions

Overall, the results of the survey were consistent with those found in the qualitative interviews. Tick identification was generally poor, there was confusion about safe and effective tick removal strategies and reports of engaging in tick checking behaviour were low. Any differences detected between the qualitative and quantitative research findings are perhaps less differences in the underlying mental processes than they are differences due to methodology. The qualitative interviews highlighted a number of behavioural drivers and barriers to performing tick protective behaviours, but they did not provide any indication of

how many people are affected by these or how often they are of importance. The quantitative survey allowed for a more in depth analysis of the issues raised in the interviews, thus providing some differing information. For instance, based on the interviews it appeared that one reason for not performing a tick check was that it was perceived to be inconvenient or a hassle. However, the survey has shown that these were the least likely barriers to performing a check. These sorts of differences illustrate the benefits of using both qualitative and quantitative methods. The next chapter will discuss how data from both of these methods was used to drive the intervention design.

CHAPTER 4: INTERVENTION DESIGN

Introduction

While several types of public information material exist within the UK to educate and warn the public about ticks, the evidence from chapters 2 and 3 suggests that it might be possible to improve them by incorporating messages which specifically target those variables which are most closely related to uptake of protective behaviours. The next stage of this PhD project was to use the qualitative interview and quantitative survey data to inform the creation of communication messages with the aim of increasing tick checking behaviour. These messages were to be presented to study participants in a subsequent randomised controlled trial in the form of web pages containing the amount and style of information that would be found in public health leaflets. A total of three interventions were designed, the first of which was a control intervention. This was an amalgamated version of two pre-existing leaflets that are available on Public Health England's (PHE) public facing website (http://www.hpa.org.uk/webw/HPAweb&HPAwebStandard/HPAweb_C/1195733767621).

While other leaflets exist and can be readily found on the internet by the general public, I chose to base the control leaflet on communication that is supported by PHE to ensure that the information is accurate and reliable. The second intervention included conventional aspects of health psychology models and behaviour change techniques. This took the information in the control intervention as its basis, but emphasised those aspects found to be particularly important as predictors of tick checking behaviour in the web survey and which are conventionally described by Protection Motivation Theory or the Health Belief Model. Finally, the third intervention was similar in that it incorporated the same evidence based changes as the second intervention. However, it also included changes that were intended to reduce levels of disgust. The data from the interviews and the survey highlighted particular areas where people expressed feelings of disgust with regard to ticks. This version of the intervention was then designed with these disgust drivers in mind and the language and focus of the intervention were adjusted accordingly in order to alleviate any disgust emotions. Full details of how each intervention was designed are included in the following sections of this chapter.

The design process involved two stages. The control and experimental interventions were initially designed based on existing materials and results from the public interviews and survey. All three versions of the intervention were then pilot tested with members of the public using a read aloud protocol to ensure maximum readability and clarity. Following this piloting the

interventions were altered as necessary in order to create the final versions for use in the pilot randomised controlled trial.

Development of the Control Intervention

The control intervention was developed based on the two existing leaflets found on the PHE website. The first of these was prepared by the New Forest District Council (see appendix 21) and the second was developed in collaboration between the Health Protection Agency (now PHE) and The Royal Parks (see appendix 22). Each provides the public with information about ticks, Lyme disease, tick avoidance strategies and advice about what to do if bitten by a tick. Both give accurate and largely similar information, but differ in terms of style. The New Forest District Council leaflet is more colourful and contains more text than the Royal Parks leaflet which is black and white and uses computer generated illustrations rather than real photographs. A full comparison of the two leaflets is given in table 4.1.

Table 4.1 Control Leaflet Comparison

Information in bold = In one leaflet but not the other

Information underlined = Difference in advice about same topic

	Royal Parks Leaflet	New Forest Leaflet
What are ticks?	Similar to spiders/mites, feed on blood, found in moist/shady areas like bracken, can't jump or fly , get on skin when you brush past something they're on, <u>mostly between April-October</u>	Tiny spider like creatures, in grassy /wooded areas, attach to passing animals (type of animal depends on tick life cycle stage), suck blood which may take 3-5 days and then they drop off, <u>peak periods are May-July and September-October</u> , some (lower) risk of bites at other times of year if weather mild
What do ticks look like?	Size, colour, development stages, feeding size/appearance	
Image showing actual tick sizes	Yes (illustration)	Yes (photos) – plus engorged tick photo
More information	Websites: HPA, NHS , CDC, EUALB	Websites: EUALB, CDC, HPA
What is Lyme disease?	Bacterial infection, uncommon in humans because only small	Illness caused by bacteria in gut of some ticks, most ticks don't

	proportion of ticks carry it, <u>found in countryside (esp. woodlands with deer eg. Richmond Park)</u>	carry it but is passed on by being bitten by infected tick, should assume any tick bite is potentially infectious , <u>infected ticks found in many areas (New Forest, East Anglia, West country, Welsh Uplands, Scottish highlands, also in other parts of Europe and NA)</u>
What are the symptoms?	3-32 days after bite from infected tick, first sign usually rash around bite site (large circle up to 50cm in diameter – can be faint on darker skin), flu-like symptoms (headaches, chills, tiredness, muscle pains, joint aches, fever), more serious complications may be weeks or months after bite if untreated (temporary facial paralysis, pain, weakness/loss of sensation in arms, legs or trunk, arthritis), symptoms resolve quickly with antibiotic treatment, early recognition/treatment important and helps prevent more serious condition	Usually few days to several weeks after being bitten, first sign usually a rash around bite site (can be up to 50cm in diameter), not usually raised, itchy or painful and clears quickly with antibiotic treatment, sometimes rash is faint and hard to see on darker skin; rashes within a few hours of tick bite are not Lyme but likely allergic reaction ; may get flu-like symptoms after rash (headaches, chills, tiredness, muscle pains, joint aches, fever), symptoms could last several weeks without treatment but usually go away quickly with antibiotics; more serious conditions sometimes develop several weeks or months after bite in those who didn't receive treatment (facial palsy, pain/tingling/loss of sensation in arms/legs/trunk, joint pain), some people may be unaware of tick bite or rash so diagnosis delayed
Image of antibiotics	Yes	No
How to minimise risk of infection	Avoid being bitten, bites don't hurt so easy to miss , check whole body when you get home (esp. head, neck and skin folds), check clothes as well, make sure to check hairline and neck esp. in young children	If work in tick areas then remove work clothes before going home (Lyme acquired through work conditions is reportable)

What to do if bitten	Remove tick ASAP, use fine pointed tweezers or tick removal tool, grasp close to the skin, pull upwards firmly/steadily without jerking/twisting; don't squeeze body as could cause regurgitation and increase risk of infection; after removal apply antiseptic to site; don't use petroleum jelly, liquid solutions, freeze or burn the tick; after removal keep an eye on site for a month to see if any redness or rash; go to doctor if symptoms develop	Remove tick ASAP, don't panic, unlikely to transmit during first few hours so removal is important ; never apply heat or chemicals as could stimulate regurgitation and increase risk of infection; check for redness around bite site, if concerned go to doctor
Pet image	Yes (illustration) – with dog saying remember to check pets for ticks too – consider carrying tweezers or remover when walking to quickly remove a tick	Included in image of prevention methods (photo)
To prevent tick bites	Wear long sleeves and trousers, tuck trousers into socks, wear closed shoes not sandals, treat pets or get tick collar, stick to paths, avoid walking through dense vegetation	Keep skin covered, trousers and long sleeved shirts, trousers into socks, shoes or boots not sandals, repellents on clothes or skin, tick check every 3-4 hours and at end of day, brush clothing before going indoors and check pets, pay particular attention to skin folds (armpits, groin) and scalp esp. in young children
Image of trousers, shirt, collar, repellent, socks, boots	Yes (illustration)	Yes (photo)
Tick removal	<u>Fine tweezers or tick removal device</u> , device has flattened hook to grip the tick, devices available to buy at Richmond Park info centre – also at vet practices and online	<u>Grasp close to skin using tweezers or fingernails</u> and pull firmly/steadily without jerking/twisting, don't squeeze/crush tick, sometimes mouth parts break off but this is unlikely to increase disease risk so just apply antiseptic , specific devices are available from vets and pet shops
Image of removal with tweezers	Yes (illustration)	Yes (photo)
Image of removal with device	No	Yes (photo)

Treatment		Early antibiotic treatment highly effective and rarely any complications, longstanding infection may require longer courses of antibiotics – early recognition important
Life cycle of ticks	No	Life cycle takes 2-3 years and involves a variety of different hosts
Image of rash	No	Yes (photo with coin to show size)
Image of deer	No	Yes (photo)

Both of the existing leaflets were studied for the use of any behaviour change techniques. As described in detail in chapter 1, behaviour change techniques are a series of intervention strategies used to try and change behaviour (Abraham & Michie, 2008). It was not expected that either leaflet had been explicitly created with these techniques in mind, but many of the techniques are common-sense approaches to presenting information. It is possible to identify the use of behaviour change techniques by applying the coding manual developed by Abraham and Michie (2008) to intervention descriptions. The manual comes with detailed instructions for use as well as detailed descriptions of each of 26 behaviour change techniques.

The Royal Parks leaflet had little link to any behaviour change techniques. There was some general information provided about the link between behaviours and health in terms of linking the importance of prompt tick removal to a decreased risk of disease transmission. The leaflet also provides written instructions regarding behaviour performance, in this case safe and effective tick removal, and models or demonstrates this behaviour with a picture. The New Forest leaflet incorporates the same behaviour change techniques, but also uses one more by loosely prompting specific goal setting. Although it does not explicitly tell people to set goals for tick checking behaviour, it does tell people when, how often and where to perform the behaviour, which could then be formed into a goal by the reader. The existing use of behaviour change techniques was incorporated into the control leaflet and used as a starting point for a greater and more deliberate inclusion of techniques in the two experimental leaflets. The inclusion of information for each section of the control intervention, formed from these two leaflets, is explained in detail below. Figure 4.1 is a copy of the control

intervention produced following amalgamation of the two existing leaflets. This version was presented to participants for initial piloting.

Figure 4.1 Control Intervention

Ticks and Lyme Disease

What are ticks?

- *Small, spider-like creatures
- *Feed by biting through skin and sucking on blood of animals (and humans)
- *When feeding they engorge with blood
- *Prefer moist, shady places, eg. Leaf litter
- *Can be found in long and short grass and wooded areas
- *Can't jump or fly so they climb onto you when you brush past them
- *Take 3 to 5 days to feed before dropping off
- *Tick life cycle is 2 to 3 years
- *There is a risk of bites any time of year, but it peaks between April and October

What do ticks look like?

Tick nymphs or larvae are about the size of a pin head or poppy seed, flat in shape and ranging in colour from brown to black. Adult ticks are slightly bigger and look like small spiders. When feeding, a tick's body will fill with blood and swell to the size of a match head, becoming purple, blue-grey or pink in colour.



Left to right: tick nymph, adult

What is Lyme disease and how can ticks become infected with it?

Ticks have three active stages in their lifecycle - larva, nymph and adult. Larvae are rarely infected with Lyme bacteria when they are newly hatched, but may become infected during their first feed. If the feeding host carries the Lyme bacteria the larva can take in the infection during its blood meal. It then drops off the host, returning into the undergrowth for many months until it matures into a nymph, when it will again seek a blood meal. If an infected nymph feeds on an uninfected animal or bird, it can transmit the infection, and this second host then becomes a "reservoir host". Following the feed the nymphs again drop back into the undergrowth and mature into adults, when they will take a final feed from a deer or other large animal, mate and lay their eggs in sheltered undergrowth.

Infected ticks are found in many areas such as the New Forest, Richmond Park, East Anglia, West Country, Welsh Uplands, Scottish highlands, also in other parts of Europe and North America.

What are the symptoms of Lyme disease?

Usually appear after a few days to several weeks after being bitten with the first sign usually being a rash around bite site. The rash is not usually raised, itchy or painful and clears quickly with antibiotic treatment. Following the rash you may get flu-like symptoms (headaches, chills, tiredness, muscle pains, joint aches, and fever) which could last several weeks without treatment but usually go away quickly with antibiotics. More serious conditions sometimes develop several weeks or months after being bitten in those who didn't receive treatment (facial palsy, pain/tingling/loss of sensation in arms/legs/trunk, joint pain).

Treatment of Lyme disease:

Early treatment is highly effective and rarely results in any complications, therefore early recognition is important.

How to prevent tick bites and minimise risk of infection:

Avoiding contact with ticks is the best way to minimise the risk of infection. By following these simple suggestions you should be able to limit your contact with ticks.

- * Wear long, light coloured trousers and closed shoes
- * Tuck your trousers into your socks
- * Use a tick repellent on your clothes and skin
- * Stick to clear pathways and try to avoid walking through dense vegetation

Checking for ticks:


Bites don't hurt so they are easy to miss which means that you should check your whole body when you get home, check clothes as well, and make sure to check the hairline and neck, especially in young children. If you work in tick areas then remove work clothes before going home. If you are going to be outside for several hours or longer then it may be useful to perform a tick check while you are still outside. For example, if you are walking you could stop every couple of hours to make sure that you haven't picked up any ticks on your clothing or skin.

What to do if bitten and how to remove a tick:

Remove the tick as soon as possible using fine pointed tweezers or a tick removal tool – these are available at many outdoor stores, pet shops and vet clinics. Grasp it close to the skin and pull upwards firmly and steadily without jerking or twisting. Don't squeeze the body as it could cause regurgitation and increase the risk of infection. After removal apply antiseptic to site. Never use petroleum jelly, liquid solutions, chemicals or freeze or burn the tick as this could cause regurgitation and increase infection risk. After removal keep an eye on the site for a month to see if any redness or rash and see a doctor if symptoms develop.



Tick removal with specific removal device



Tick removal with tweezers

The control intervention was drafted in a manner that meant it would be applicable to all areas of the UK rather than being tailored to a specific location as was the case with the pre-existing leaflets. All topics covered in the pre-existing leaflets were incorporated into the control intervention, even if the topic only appeared in one of the leaflets and not the other. As such, the following topics were included: what are ticks; what do ticks look like; what is Lyme disease and how can ticks become infected with it; what are the symptoms of Lyme disease; treatment of Lyme disease; how to prevent tick bites and minimise the risk of infection; and tick removal. In addition to these topics taken from the pre-existing materials there were several points that needed further consideration. Firstly, although tick checking was mentioned as a prevention strategy, it had not been given a dedicated section in either of the pre-existing leaflets. I chose to create a specific tick check section in the control intervention because this was the prevention behaviour that was the main outcome variable for the study. The two experimental versions of the intervention focused on tick checking behaviour in more detail than was done in either of the pre-existing leaflets and it was therefore necessary to ensure that the topic was covered in a similar length and focus within the control. In this way it would be easier to dismiss any potential differences in tick checking behaviour as a result of insufficient coverage or focus on this topic in the control group. The information provided about checking stated the importance of engaging in a check and when it could be useful, but it gave no details about how to actually perform the check. Secondly, the section of the control intervention that addressed what Lyme disease is and how ticks can carry it was considerably longer than the corresponding sections in either of the experimental interventions. This was because altering the control leaflet to be fit for purpose among the experimental groups resulted in the overall length of the leaflets being increased. In order to ensure that differences in overall length did not affect the outcomes in the eventual RCT, I made the control version of equal length by incorporating some irrelevant information about the tick life cycle and how ticks can become infected into the Lyme disease section. Much of this detail was also included in the New Forest leaflet, including an image of the tick life cycle and of a deer as a host animal. This information was considered irrelevant for this study because although it is accurate, it does not provide participants with any more details about how to perform protective behaviours or encourage them to engage in these behaviours. In short, this material did not address any of the barriers, concerns or questions that were raised by participants in either the interviews or the survey, but acted only as 'filler' material. Thirdly, in the tick removal section the New Forest leaflet included the use of fingernails as an appropriate removal strategy. The use of fingernails was not recommended in any of the

expert interviews as an effective or safe removal strategy and was therefore not included in the control intervention.

Initial Development of Intervention Based on Conventional Models within Health Psychology

The control intervention served as the basis for each of the two experimental interventions. The structure of the intervention was kept largely the same as the control in order to reduce the possibility that differences in length or layout might account for any differences observed in the pilot randomised controlled trial. Table 4.2 describes each amendment made to the control intervention in order to produce the intervention based on conventional models within health psychology, together with a summary of why each change was made. Details of how the data from the interviews and survey drove the development and design of the intervention are described in the following sections.

Table 4.2 Inclusion justification for intervention based on models within health psychology

WHAT	WHY	HOW
What are ticks?	Included in control. Addresses knowledge/awareness of ticks which may be lacking for some participants as indicated by the interview and survey data.	Nearly identical to the control, but slightly shorter. Use of straightforward text so that concepts are clear and not lost among superfluous information.
What do ticks look like?	Included in control. Addresses issues surrounding participant ability to correctly identify a tick as found in the interviews, but particularly in the survey.	Identical to control as the information is clear and concise. Includes an image for clarity – a different image was used compared to control leaflet to show all stages of development and with a clear size reference.
What is Lyme disease?	Included in control. Expanded/revised to address questions about risk perception such as the likelihood of being bitten, tick locations, etc. as raised in interviews. Also addresses low participant knowledge/awareness of disease as indicated by the interview data.	Similar to control version, but includes details of current number of UK cases, where these ticks can be found. Also incorporated the behaviour change technique of providing information on behaviour-health link and the consequences of behaviour (i.e. increased chance of being bitten

		if not practicing protective behaviours).
How severe is Lyme disease?	Not included in control. Addresses questions about risk perceptions (particularly disease severity) as raised by interview participants. Also addresses knowledge/awareness of what signs and symptoms to look out for if bitten which was shown to be low in the interviews.	Similar to control version in terms of the information about severe symptoms, but reworded in order to highlight the importance of early treatment. The image of a Lyme rash was removed as the ability to identify a rash is irrelevant to engaging in tick prevention behaviours. Perceived severity is an important part of health psychology models of behaviour change.
How likely am I to get Lyme disease?	Not included in control. Addresses participant questions about risk perception (particularly disease likelihood and bite likelihood) as raised by interview participants. Also addresses knowledge/awareness of habitats or locations where ticks can be found.	Similar to control version in the information about tick locations, but the information about number of cases is a new inclusion. Perceived susceptibility is an important part of health psychology models of behaviour change.
How can I prevent tick bites and minimise risk of infection? Perform a tick check!	<p>Not included in control. Addresses issues of low knowledge/awareness of tick checking behaviours as shown in interviews.</p> <p>Also included to address issues about not knowing how to perform a tick check effectively or even knowing that a tick check existed which were both identified in the interviews and survey as barriers to checking behaviour. Also addresses issue of mobility barrier to performing a check as raised in the interviews.</p> <p>Includes a section to address the hassle/forgetfulness barriers to tick checking behaviour as were raised by participants in both the</p>	<p>Control version does mention tick checking although not in any detail. This version is more in depth in order to address the barriers to behaviours. It incorporated the behavioural change technique of providing general encouragement about performing the behaviours as well as more information on the behaviour-health link.</p> <p>Short, clear description of what a tick check is, how to do it, when to do it, and ways to avoid the identified barriers to practicing the behaviour. To do this I incorporated the behavioural change techniques of barrier identification and solution, providing general encouragement to practice the</p>

	interviews and survey.	behaviour, specific goal setting, use of prompts/cues, social support, time management and introducing self-monitoring as a way to encourage the behaviour.
What to do if bitten and how to remove a tick	Included in control. Addresses the availability of tick removal devices as questioned by participants in the interviews; addresses knowledge/awareness of correct removal as was shown to be low in both the interviews and the survey; addresses the issues of low self-efficacy surrounding removal as reported in both the interviews and survey.	Similar to control version, but in bullet points for ease of reading. Includes an image of tick removal as a demonstration. Incorporates the behavioural change techniques of demonstrating the behaviour (through an image) and providing instruction about how to perform the behaviour.
Other prevention strategies	Included in control.	Identical to control.

As demonstrated by the qualitative interview and quantitative web survey data, the area where most behaviour change could be gained was the performance of a tick check. Drivers and barriers to the uptake of tick checking behaviour as identified through the public interviews and survey were addressed in the first experimental intervention, particularly through the use of psychological theory and behaviour change techniques.

Firstly, both the public interviews and the survey found a number of barriers to tick checking performance. Evidence from the web survey suggested that not knowing how to perform a tick check was a key reason for not performing one. Among survey participants rates of tick checking were very low with only 7% of participants saying that they checked themselves for ticks 'almost always' or 'always' after walking. Common reasons for failing to perform a check were not knowing how to perform one and not knowing what a tick check was. Interviews also highlighted issues of mobility as a potential barrier to performing a tick check. Both the interviews and the survey found that one of the main reasons reported for not engaging in tick protective behaviours was forgetfulness. For instance, 42% of survey respondents said they forget to perform tick checks after walking. In addition to forgetfulness, a number of interview participants also suggested that performing a tick check could pose too much hassle and inconvenience. As a result of these barriers to checking behaviour, the first experimental

intervention included a section of text explaining not just that a tick check should be performed (as in the control intervention), but also how it should be performed. In brief, this emphasised the importance of performing a check effectively both while walking and after walking and provided a series of clear strategies aimed at eliminating the behavioural barriers identified in the interviews and survey data. Crucially, each of these strategies also included an example of how it could be effectively used.

In addition to addressing the barriers to performing tick checking behaviour, the first experimental intervention was also designed to target the drivers of tick checking behaviour as a way to increase engagement in protective behaviours. Knowledge was identified as a major and multi-faceted driver affecting the uptake of tick checking behaviour. It encompassed not only the provision of general information about what a tick is or where it might be found, but also the more specific concepts of disease severity, disease likelihood and tick removal. The survey data confirmed the idea that a greater knowledge of ticks was associated with reports of engaging in tick protective behaviour. Findings from both the public interviews and the survey indicated that knowledge and awareness of what a tick is were sometimes lacking, and ability to correctly identify a tick was particularly low. The control intervention already included details of what ticks are, what they look like and what Lyme disease is so this information was adopted for use in the experimental intervention.

Details about disease severity were requested during the public interviews, with participants suggesting that this would play a crucial role in their decision to engage in protective behaviours. Perceived severity is an element of many health psychology theories, so this provided further impetus to include it as its own section within the larger intervention. The information was similar to that provided in the control intervention, but was reworded in order to highlight the importance of early treatment. The image of a Lyme disease rash was also removed because it was deemed to be irrelevant given that the ability to identify a rash has no bearing on one's ability to perform a tick preventive behaviour and also because the image gives no indication of disease severity.

Likelihood data were not included in the control intervention at all, but the attention it received from participants and the focus it receives in various theories within health psychology indicated that it should have a dedicated section. One behaviour change technique was used here. Participants were provided with information about the behaviour-health link, or more simply, they were exposed to the message that the behaviours they do or do not

engage in can influence their health. For example, walking in an area where ticks may be present could potentially result in being bitten by a tick and developing Lyme disease.

The provision of information about what to do if bitten and how to go about correctly and safely removing a tick is something that was covered in the control intervention, but was expanded on in both experimental interventions. During the public interviews, participants were often unaware of the existence of specific tick removal devices or were unaware of where they could be found. The interviews and survey also highlighted the fact that knowledge and awareness of the correct removal process was low, with only 30% of survey participants selecting only the appropriate removal strategy. Furthermore, removal self-efficacy was also low with only 40% of survey participants reporting that they 'agree' or 'strongly agree' that they would feel confident about removing a tick from themselves. The information covered in this section of the intervention addressed these gaps in knowledge and tried to increase feelings of self-efficacy by including images of tick removal. Behaviour change techniques were also incorporated here with a demonstration of removal behaviour as shown with the image and a provision of instruction about how to actually perform the behaviour. Although the main messages in this section remained the same as in the control leaflet, they were restructured into a step-by-step process so that it was a quicker and clearer section to read.

Finally, many of the predictor variables were addressed throughout the intervention rather than in particular sections. For example, the predictor variables of a tick check being too time consuming or a task that is easily forgotten are addressed in the tick check section where they are discussed as particular barriers to performing the behaviour and solutions are offered. Perceptions of control and the ability to determine contact with ticks are also covered in the tick check section where participants are encouraged to engage in the behaviour and to feel that it is worthwhile and easy to do. The predictor variable of perceiving that enough information on ticks and tick-borne disease is available is a more general request that is addressed by the overall provision of information in the interventions.

In addition to the use of conventional health psychology theory, behaviour change techniques played an important role in the design of this intervention. A total of seven techniques were used specifically to encourage uptake of tick checking behaviour. Firstly, barriers to the performance of tick checking behaviour were identified and solutions were provided. Secondly, participants were given general encouragement to perform tick checks. Thirdly, specific goal setting was suggested as a useful technique for increasing tick checking

behaviours. Fourth, participants were encouraged to use prompts or cues to help them remember to practice tick check behaviours. Fifth, social support was encouraged. Sixth, time management was suggested as a useful tool for behavioural uptake. Finally, self-monitoring was suggested as a way to increase engagement in the behaviour.

The information about tick checking behaviour was presented in a separate text box within the intervention and with slightly larger text in order to make it the focus of attention.

Initial Development of the Disgust Reduction Intervention

The disgust reduction intervention was based on the first experimental intervention and was therefore nearly identical in many areas. Table 4.3 describes each amendment made to produce the disgust reduction intervention, together with a summary of why each change was made. Details of how the data from the interviews and survey drove the development and design of the intervention are described in the following sections to address emotions of disgust.

Table 4.3 Inclusion justification for disgust reduction intervention

WHAT	WHY change this from the version based on models of health psychology	HOW this differs from the version based on models of health psychology
What are ticks?	Included in control and intervention 2 and altered here to address potential evocation of disgust through references to blood.	Nearly identical to control and intervention 2. Removed references to blood or blood sucking where possible to reduce elements of disgust as in interviews participants referenced blood/blood sucking as a cause of disgust.
What do ticks look like?	Included in control and intervention 2 and altered here to reduce potential for disgust reactions.	Nearly identical to control and intervention 2, but removed references to ticks filling with blood to reduce elements of disgust (as above).
What is Lyme disease?	Included in control and intervention 2 and there was no need to change this for the disgust reduction intervention.	Identical to control and intervention 2.

How severe is Lyme disease?	Not included in control, but is in intervention 2 and there was no need to change it here.	Identical to control and intervention 2.
How likely am I to get Lyme disease	Not included in control, but is in intervention 2 and there was no need to change it here.	Similar to control version and identical to intervention 2.
How can I prevent tick bites and minimise risk of infection? Perform a tick check!	<p>Similar to intervention 2, but now also addresses issues of potential behavioural avoidance of tick checking as a result of disgust towards ticks.</p> <p>Included a section on ticks being disgusting to address self efficacy concerns raised by participants in the interviews and survey about being able to remove a tick themselves.</p>	Identical to intervention 2, except for the paragraph specific to disgust, which provides short, reassuring text about the ease and importance of removal as well as highlighting the greater negative consequences of contracting a tick-borne disease compared to removing a tick. Incorporates the behavioural change techniques of providing information on the behaviour-health link and the consequences of not performing protective behaviours. Also provides general encouragement about removal.
What to do if bitten and how to remove a tick	Included in control and intervention 2, but focus here addresses issues of low self-efficacy surrounding removal as reported in both the interviews and the survey.	Similar to intervention 2, but with more focus on increasing self-efficacy and building removal confidence as in the interviews and survey participants referenced removal of a tick as disgusting. Incorporates the behavioural change techniques of identifying barriers (in this case, concerns that they will not be able to remove a tick themselves) and providing solutions and planning social support (getting someone else to help with removal if necessary).
Other prevention strategies	Included in control and intervention 2.	Identical to control and intervention 2.

The survey data showed that those people who reported greater levels of disgust towards ticks were less likely to have performed a tick check. The interview data also indicated that participants often expressed feelings of concern about both the tick check and the tick removal

process. As a result, in order to help participants to reduce, or at least to overcome, this behavioural avoidance associated with tick checking it was necessary to provide reassurance about the effectiveness and ease of the behaviour. This reassurance was also reinforced regarding tick removal with this section of the intervention making it clear to participants that having to deal with a tick-borne disease as a result of a bite would be far more unpleasant than spending a minute checking for a tick and removing safely. This made use of the behaviour change technique of providing information on the behaviour-health link and the consequences of performing or not performing the recommended behaviour. In addition, the technique of general encouragement has also been employed in the attempt to change behaviour.

Interviews run with members of the public identified references to blood and the feeding of ticks on blood as causes of disgust. Therefore, in order to reduce the feeling of disgust, this version of the intervention used a more technical language and avoided direct references to blood or engorgement.

The disgust reduction version of the intervention incorporates the information and techniques listed above, but also focused more on increasing self-efficacy and on building confidence about the tick removal process. During the interviews with members of the public there was discussion about tick removal which highlighted that people often felt unsure about what they were supposed to do and how to do it. There were concerns over conflicting information and a general feeling that if bitten by a tick there would be anxiety about removal. It is hoped that these issues are addressed by focusing the communication on providing reassurance to people regarding tick removal and by suggesting a solution for those who still feel they would be unable to engage in the process.

Behaviour change techniques unique to this leaflet were also included. These were the identification of barriers and provision of solutions (lack of removal confidence and the suggestion to have a GP help with removal) and the planning of social support (arranging for someone else, whether they be a friend or a medical professional, to aid in removal).

Intervention Piloting and Read Aloud Protocol

Methods

Design

Following the initial intervention design and drafting process, two rounds of one-to-one read-aloud interviews were held with London-based participants who engage in outdoor activities to pilot test intervention materials. All interviews took place in February and March 2013 and were conducted over the telephone.

Participants

Participants were resident in London and were involved in outdoor activities such as walking or rambling which took them to non-urban areas. Participants were drawn from a sample of the King's College London Mindsearch database. This is a database of approximately 900 members of the public who are based in London and who have indicated that they are happy to be contacted about opportunities to take part in research trials. To encourage participation each study participant was given a £10 voucher for use in a variety of high street shops. Participants were initially contacted by email to invite them to take part in the study and once interest was expressed they were contacted by telephone for the actual pilot testing interview.

Procedure

Participants were all asked to arrange a suitable time for their interview. Each interview was approximately 20 to 25 minutes in length. The interviews were audio recorded and were later reviewed by the researcher. In line with the King's College London ethics approval procedures (ethics approval code: PNM/12/13-2) the anonymity of each participant was maintained. Participants were provided with consent forms describing their right to withdraw from the study and the contact details of the researchers if they had any further questions after they had participated in the interview.

There were three different intervention versions which included the control and two experimental versions. Each participant, regardless of intervention version, was sent the intervention by email and asked to read it through to themselves before being asked a series of general questions about the intervention. Following this, they were asked to read aloud through each section of the intervention with questions and discussions about each part of text. This is called a read-aloud protocol and is ideal for determining the clarity, usefulness and understanding of intervention messages and also has the ability to aid in the identification

of potential improvement areas. It allows participants to verbalise their perceptions about the topic while they are reading through the intervention and helps to determine whether the material is being interpreted as intended (Johnson & Christensen, 2012). Please see appendix 23 for the full discussion guide that was used for each intervention. Each version of the intervention was initially piloted with three participants. Suggestions and changes arising from these interviews were then used to update the interventions and each of the two experimental interventions was piloted again. This second round of piloting had four participants and each participant was given both of the experimental interventions and was asked to read through and compare them.

Analysis

Each interview was reviewed for comments about the clarity and readability of the messages as well as potential areas where improvements could be made. Initially this analysis was done on each individual interview before aggregating the data to identify themes within each intervention group.

Results

First round of interviews

Piloting of the control intervention found that participants reported that they would be a bit more likely to practice precautionary behaviours after having read the intervention. Checking clothes for ticks was a behaviour that participants reported that they would engage in, but no mention was made of performing a tick check of the body. Participants felt that although they knew the intervention was telling them about the importance of performing a check, they did not feel as though there were any instructions on how to carry out the check. Levels of disgust were reported to have stayed the same or, in one case, worsen. Confidence in tick removal abilities appeared to rise after reading although participants suggested that it might be better to present this information in bullet point form for ease of accessibility. Overall, participants said that perhaps there was too much information included on topics such as the tick life cycle and that instead it might be better to give this space to details of disease likelihood. All images were reported to be useful.

As a result of the first round of interviews it was decided that the control intervention would remain unchanged. This was partly because it was based on existing interventions and was meant as a reflection of this, but also because it produced the expected results. The changes suggested to the control intervention were mostly the changes that were made to create the

health psychology and disgust interventions. This was encouraging given that these changes were based on initial mental model interviews with members of the public in addition to behaviour change theory. That the suggestions made during the read aloud interviews matched the findings of the earlier interviews provided some evidence that the experimental interventions could be successful.

All participants reviewing the intervention based on conventional models of health psychology reported being more likely to engage in tick checking behaviour after having read the information. The specific tick checking section of the intervention was said to be easy to read and made people feel that they would be capable of carrying out a check after reading. The behavioural reminder strategies were deemed useful and one participant explained that it was good to have active suggestions of what should be done. Levels of disgust were largely reported to be similar before and after reading the information, although there was mention that they felt better for having been provided with useful information. Removal confidence was reportedly raised for all participants who said they found this section particularly clear and important. The removal instructions were also said to make the process of removal seem easier and more straightforward than expected. The key points picked out by participants were the importance of performing a tick check and also engaging in other precautionary behaviour. Participants reported finding the disease likelihood and severity information useful, but said that they felt information about earlier symptoms was lacking as was clarification about the permanency of the disease and symptoms. All images were said to be useful and appropriate.

After reading the disgust reduction intervention, participants all reported being more likely to engage in prevention strategies, particularly the use of tick checks both during and after walking. Information on tick checking was said to be helpful and all participants reported that they would feel confident in performing a check. One participant also said it was useful because it was a quick and easy behaviour to perform and did not take a lot of prior planning. The tick check reminders also received favourable feedback with participants saying that they seemed like sensible, realistic suggestions. Disgust was reported to decrease slightly for two participants after reading and the remaining participant reported low levels of disgust prior to reading the intervention so there was no real need to reduce disgust. When asked, those with some decrease in disgust said that it was a result of the reassuring or calming nature of the information or because the information helped them view ticks more as a nuisance rather than something to be feared. Removal confidence was increased after reading the intervention

material with participants saying that the advice made removal seem more routine and easy to perform. One person mentioned that prior to reading the intervention they would have felt “panicky” about the prospect of removing a tick, but that the intervention helped to reduce this feeling. Key messages of the intervention were reported to be ability to correctly identify a tick, performing a tick check and using correct removal strategies. An area that participants thought could use clarification or more information was the section explaining Lyme disease. As with the intervention based on conventional models of health psychology, participants wanted to know early symptoms of disease, but the disease severity and likelihood information was deemed useful and informative without being sensationalist. One participant also suggested that it could be useful to mention that you do not feel a tick biting you, therefore this makes performing a tick check very important.

Given these findings, a number of changes were made to both of the experimental interventions. Because the disgust reduction version is based upon the version incorporating models of health psychology, many of the changes made to one applied to the other. This was further justified by the experimental interventions receiving similar feedback during the interview process. Therefore, both experimental interventions were altered to include information about early Lyme disease symptoms and the permanency of symptoms. Changes unique to the disgust reduction intervention at this stage were simply to change the tick removal images to those that were used for the first experimental intervention as the cartoon versions were causing confusion, while no negative comments were made about the photograph versions. The key messages were successfully picked out of each experimental leaflet by participants, so there was no need to make any major changes to the layout or focus of the messages.

It proved more difficult to determine the effect of the disgust reduction messaging. Participants were asked about levels of disgust towards ticks before and after reading an intervention and it appears as though participants who received the disgust reduction intervention may have experienced a reduction in disgust, but it is difficult to tell whether this is much changed compared to the other experimental intervention and whether it is in fact the disgust reduction messaging that elicited the change. When participants were asked either how their disgust had been alleviated, or how they felt it could successfully be alleviated, they tended to link it to feelings of reassurance, suggesting that it was not really about getting rid of disgust altogether, but rather being able to manage feelings of disgust. The disgust reduction intervention already framed much of the information in a reassuring manner so the only room

for further reassurance was in the disease severity and likelihood sections. However, it was decided that providing reassurance about the low likelihood of developing disease would remove the impetus to engage in tick protective behaviours, therefore these sections were kept the same.

Review by topic expert

After the initial round of read aloud piloting, the interventions were shown to a colleague in the Medical Entomology and Zoonoses Ecology team within Public Health England in order to ensure that the messages regarding ticks were accurate. The control intervention remained the same as it was meant to be based on the existing materials, but some minor changes were made to the two experimental versions. Firstly, rather than giving a very specific amount of time that it takes for a tick to feed such as '3 to 5 days'; this was altered to say a more general 'several days' as it was felt that this would encompass a wider range of tick bite experiences that may fall outside of 3 to 5 days. Secondly, the interventions initially stated that although tick bites can happen throughout the year they are most likely between April and October. This was changed to say that a risk of bites exists all year round because this was seen to be a clearer message and could help highlight the fact that people need to take precautions whenever they are in potential tick habitats. Finally, instead of providing a list of places where ticks can be found in the UK, the interventions were changed to give a couple of examples of tick locations and said that these were among other locations in the UK. This was because simply providing a list of locations might make people think that these are the only areas where ticks are found, whereas in reality they are found in many locations throughout the UK.

Second round of interviews

Prior to reading the intervention materials, participants in this round of pilot testing all reported that they did not currently practice any protective behaviours against ticks. Reasons for this included a lack of awareness both about ticks in the UK and also about the risk that they could pose. Post-interventions, each participant said that they would be more likely to engage in protective behaviours. Removal confidence was also low among two participants prior to reading the interventions, but was reported to have been raised by the end of the interview. The other participants initially reported feeling fairly confident in their ability to remove a tick if necessary, although they both conceded that after reading the interventions they felt much clearer about how to go about removal safely which they may not have done previously.

This round of pilot testing got participants to look at both the intervention based on conventional models of health psychology and the disgust reduction intervention. This was done to determine whether there was a preference between the two versions as this was not obvious from the first round of piloting. Overall, participants felt that both versions of the intervention were acceptable and provided useful and appropriate information about ticks and tick-borne disease. The majority of participants reported that while they liked the intervention based on conventional models of health psychology, they felt it was important to include the extra information targeting disgust which could be found only in the disgust reduction intervention. Participants said that the extra disgust reduction messaging was useful because it provided reassurance and could potentially make someone who is uncomfortable with the topic less prone to panic. Participants also felt that the more reassuring tone helped to make the whole process of tick prevention and removal more manageable, with one participant saying they felt it was particularly important that the intervention highlighted that checking for and removing ticks was preferable to dealing with a tick-borne disease. However, one participant reported that while they would like to have some of these reassuring messages included, they were not keen on the section entitled 'But ticks are disgusting', which they felt would be more appropriate in an intervention targeting children. Their reasoning for this was that they saw ticks as a nuisance which could be dealt with through a common sense approach which most adults would be happy to engage in. In addition to this, participants had mixed feelings towards the inclusion or exclusion of text referencing blood with two participants reporting that they felt it could be too much unnecessary detail to use terms like 'engorged', while others found the information important and useful even if it was somewhat disgust provoking.

Based on the feedback reported above, no further changes were made to the experimental interventions following the second round of read aloud pilot testing. Areas of the interventions which had been updated based on comments from the first round of piloting and the review by a topic expert were not subject to any questions or concerns during the second round pilot interviews, so these revisions were deemed appropriate. Although there were mixed reactions to the removal of blood references in the disgust reduction intervention, I decided to keep the text the way it was in order to test this as part of the overall techniques employed to reduce disgust as based on the existing literature.

Summary of changes made as a result of piloting

No changes were made to the control intervention as it was based on existing leaflets.

Following the first round of pilot interviews the following changes were made to the experimental interventions:

- *Both* interventions had more details added about early Lyme disease symptoms and symptom permanency
- *Only* the disgust reduction intervention had a sentence added to reassure people that feeling disgust towards ticks or tick removal was normal
- The cartoon tick removal images on the disgust reduction version were changed to the same photographic tick removal images found on the intervention based on models of health psychology

Changes made to both of the experimental interventions after review by a topic expert included:

- Changing tick feeding time from '3 to 5 days' to a more general 'several days'
- Saying that there is a risk of tick bites throughout the year rather than specifying that it is more likely from April through October
- Only providing a couple of locations as examples of places that ticks can be found among other places rather than providing an exhaustive list of locations

No further changes were made to either intervention following the second round of pilot interviews.

A copy of the final version of the first experimental intervention which was based on conventional models in health psychology can be seen in figure 4.2.

Figure 4.2 First experimental intervention

Ticks and Lyme Disease

What are ticks?


- Small, spider-like creatures
- Feed on blood of animals (and humans)
- When feeding they engorge with blood
- Prefer moist, shady places like leaf litter
- Can't jump or fly so they climb onto you when you brush past them
- Take several days to feed before dropping off
- There is a risk of bites any time of year

What is Lyme disease?

Lyme disease is an illness caused by bacteria in the gut of some ticks. It is possible for humans to get the disease if they are bitten by an infected tick. Early symptoms often include flu-like symptoms and a circular rash at the bite area. These symptoms end with treatment.

What do ticks look like?

Tick nymphs or larvae are about the size of a pin head, flat in shape and range in colour from brown to black. Adult ticks are slightly bigger and look like small spiders. When feeding, a tick's body will fill with blood and swell in size, becoming purple, blue-grey or pink in colour.



Left to right: tick larvae, nymph, adult male, adult female

How severe is Lyme disease?

Early treatment of Lyme disease is highly effective and rarely results in complications. However, without timely treatment more serious conditions can develop such as joint pain and pain or loss of sensation in arms, legs or trunk and can be more difficult to treat. Early recognition is important, but the best way to avoid disease is by practicing some easy tick prevention methods.

How likely am I to get Lyme disease?

Between 1000 and 3000 people get Lyme disease in the UK each year. Not all ticks carry disease, but those that do have been found in places such as the New Forest, Richmond Park, East Anglia, West Country, Welsh Uplands, and Scottish highlands, among other locations in the UK.

How can I prevent tick bites and minimise the risk of infection? Perform a tick check!

A tick check is a way of ensuring that you haven't picked up a tick while outdoors and it's very easy to perform. You should do the check every few hours if you're outdoors for a longer period of time – just look over your clothes and body for any ticks and feel around the hard to see areas like behind the knees. When you get home or when you've returned from outdoors perform a more thorough check by removing your clothes and having a good look and feel for any ticks – a mirror can be useful for the harder to see areas. If you usually have a shower or bath after walking, that is an ideal time to check yourself.

How to remember

Checking for ticks is easy, effective and very important. But it can be difficult to remember to do it. Here are some things you can do to make sure you remember to check after every walk.

1. **Set goals for yourself** – decide when and where you could do a tick check (e.g. do a tick check every time you return home from walking)
2. **Set aside a specific time to do it** – perform a quick tick check each time you stop during an outdoor activity such as walking so that it becomes part of your normal routine or habit
3. **Get others involved** – if you go walking in a group get everyone to remind each other about checking
4. **Find ways to remember to perform a tick check which work for you** - for example, if you check your walking gear for brambles, etc. after walking then add a check for ticks at the same time; if you drive to your walking location you could leave a tick remover/tweezers on the seat of your car so that you remember to check for ticks before driving home


What to do if bitten and how to remove a tick:

If you are bitten, here are some useful tips for quick and safe tick removal. These are the only safe and effective ways to remove ticks:


1. Don't panic! Disease transmission doesn't happen immediately – it can take hours or days so quick removal can help you to avoid any infection.
2. Using fine pointed tweezers or a tick removal tool remove the tick as soon as possible. Tick removers can be found in many pet shops and outdoor stores as well as online.
 - Remove by grasping it as close to the skin as you can and pulling upwards firmly and steadily
 - Avoid squeezing the body as it could cause the tick to regurgitate and increase the chance of infection
3. Once removed, apply antiseptic to the bite area and monitor it for any changes over the next few weeks.
4. If redness or a rash appears then visit your GP.

Other prevention strategies:

- Wear long, light coloured trousers and closed shoes
- Tuck your trousers into your socks
- Use a tick repellent on your clothes and skin
- Stick to clear pathways and try to avoid walking through dense vegetation



Tick removal with specific removal device



Tick removal with tweezers

A copy of the final version of the second experimental intervention which uses disgust reduction messaging can be seen in figure 4.3.

Figure 4.3 Second experimental intervention

Ticks and Lyme Disease

What are ticks?


- Small, spider-like creatures
- They bite animals and sometimes people
- Prefer moist, shady places like leaf litter
- Can't jump or fly so they climb onto you when you brush past them
- Take several days to feed before dropping off
- There is a risk of bites any time of year

What is Lyme disease?

Lyme disease is an illness caused by bacteria carried by some ticks. It is possible for humans to get the disease if they are bitten by an infected tick. Early indications often include flu-like symptoms and a circular rash at the bite area. These symptoms end with treatment.

What do ticks look like?

Tick nymphs or larvae are about the size of a pin head, flat in shape and range in colour from brown to black. Adult ticks are slightly bigger and look like small spiders. When feeding, a tick's body will become much larger.



Left to right: tick larvae, nymph, adult male, adult female

How severe is Lyme disease?

Early treatment of Lyme disease is highly effective and rarely results in complications. However, without timely treatment more serious conditions can sometimes develop such as joint pain and pain or loss of sensation in arms, legs or trunk and can be more difficult to treat. Early recognition is important, but the best way to avoid disease is by practicing some easy tick prevention methods.

How likely am I to get Lyme disease?

Between 1000 and 3000 people get Lyme disease in the UK each year. Not all ticks carry disease, but those that do have been found in places such as the New Forest, Richmond Park, East Anglia, West Country, Welsh Uplands, and Scottish highlands, among other locations in the UK.

How can I prevent tick bites and minimise the risk of infection? Perform a tick check!

A tick check is a way of ensuring that you haven't picked up a tick while outdoors and it's very easy to do. You should do the check every few hours if you're outdoors for a longer period of time – just look over your clothes and body for any ticks and feel around the hard to see areas like behind the knees. When you get home or when you've returned from outdoors perform a more thorough check by removing your clothes and having a good look and feel for any ticks – a mirror can be useful for the harder to see areas. If you usually have a shower or bath after walking, that is an ideal time to check yourself.

"But ticks are disgusting!"

It is perfectly normal to feel disgusted by ticks – it's just your body's way of telling you that you should avoid being bitten by them. Ticks are generally quite slow moving and it takes time for them to bite you, so the regular performance of tick checks can help avoid bites. Some people find removing a tick a little daunting the first time they do it but it's actually very easy to do. The important thing to remember is that dealing with a tick-borne disease would be much more unpleasant and long lasting than taking a minute to remove a tick.

How to remember

Checking for ticks is easy, effective and very important. But it can be difficult to remember to do it. Here are some things you can do to make sure you remember to check after every walk.

1. **Set goals for yourself** – decide when and where you could do a tick check (e.g. do a tick check every time you return home from walking)
2. **Set aside a specific time to do it** – perform a quick tick check each time you stop during an outdoor activity such as walking so that it becomes part of your normal routine or habit
3. **Get others involved** – if you go walking in a group get everyone to remind each other about checking
4. **Find ways to remember to perform a tick check which work for you** - for example, if you check your walking gear for brambles, etc. after walking then add a check for ticks at the same time; if you drive to your walking location you could leave a tick remover/tweezers on the seat of your car so that you remember to check for ticks before driving home



What to do if bitten and how to remove a tick:

If you are bitten, here are some useful tips for quick and safe tick removal. These are the only safe and effective ways to remove ticks – other techniques could increase your chances of infection:

1. Don't panic! Some people find it quite upsetting or difficult to deal with removing a tick, and while it isn't a particularly pleasant experience it isn't painful and it can be dealt with very quickly and easily. If you feel uncomfortable about removing the tick yourself or it's in a difficult to reach location then ask someone for help.
2. Using fine pointed tweezers or a tick removal tool remove the tick as soon as possible. Tick removers can be found in many pet shops and outdoor stores as well as online.
 - Anybody is capable of safely removing a tick – simply grasp it as close to the skin as you can and pull upwards firmly
3. Once removed, apply antiseptic to the bite area and monitor it for any changes for a few weeks.
4. If redness or a rash appears visit your GP.

Other prevention strategies:

- Wear long, light coloured trousers and closed shoes
- Tuck your trousers into your socks
- Use a tick repellent on your clothes and skin
- Stick to clear pathways and try to avoid walking through dense vegetation

Tick removal with specific removal device

Tick removal with tweezers

Discussion

Links to previous research

In an effort to ensure that as many techniques to reduce disgust as possible were included, a further search of the literature was done for any disgust reduction research. Little research has been done to look at the most effective methods for reducing levels of disgust. Where research has been done, it tends to focus on disgust as an aspect of a clinical condition such as obsessive compulsive disorder or anxiety rather than more general feelings of disgust; however aspects of this research are still of relevance to general disgust reduction. Studies have shown that disgust appears to be resistant to extinction (Olatunji, Forsyth, & Cherian, 2007; Mason & Richardson, 2010), meaning that typical cognitive behaviour style therapy where exposure forms a large part of the treatment may be unlikely to reduce disgust (Mason & Richardson, 2012). Mason and Richardson (2012) suggest a number of strategies that could potentially be effective for reducing disgust reactions. While some of these strategies are more suited to clinical treatment, there are several that could be applicable to this particular study. Disgust appears to be a visceral reaction that is disconnected from rational reasoning (Mason & Richardson, 2012). In this way, instead of trying to convince someone that an object is not disgusting, it might be more effective to focus on what it is about it that they find disgusting. This is done through conceptual reorientation, which ultimately aims to change how someone views a stimulus (Mason & Richardson, 2012). By deconstructing the offensive or disgusting object and reframing it in a more detached or clinical perspective it might be possible to reduce levels of disgust. This technique was used in the disgust reduction intervention with regards to the language used to describe how ticks feed. Rather than talking about sucking the blood and engorgement, the language was altered to be 'cleaner' and more clinical. Mason and Richardson (2012) also suggest that challenging secondary appraisals could help to reduce disgust. This puts the focus on one's perceptions of one's ability to cope with disgust, rather than focusing on the stimulus. In this case, the intervention focuses on reassuring participants that they will be able to perform a tick check and tick removal effectively despite feelings of disgust. Finally, it has been suggested that disgust could potentially be reduced through the normalisation of disgust responses (Mason & Richardson, 2012). Educating people about the role of disgust could help them to view it as a normal response, rather than as something which should cause them worry. This was incorporated into the disgust reduction intervention by including a sentence that tells participants that feelings of disgust towards ticks are completely normal.

Both the interviews and the survey revealed that members of the public were largely unaware, or at least unclear, about the safest and most effective way to remove a tick. Methods such as the use of Vaseline or burning it off with a cigarette were mentioned and were often chosen in combination with the correct removal option in the survey, indicating confusion based on current information and recommendations. Existing leaflets and other information sources tend to instruct people on how to remove a tick, but also address removal misinformation by including details on how a tick should not be removed. This is a well intentioned, common sense approach to redressing the misunderstandings surrounding the tick removal process. However, research suggests that it may do more harm than good. Studies have shown that people are more likely to remember the gist of a statement than they are to remember the details of presentation or context (Skurnik, Yoon, Park, & Schwarz, 2005; Skurnik et al. 2007). This leads to people 'misremembering' information or tending to recall false information as true. As a result of these findings the two experimental interventions in this study emphasize the appropriate way to remove a tick and do not talk about any removal myths or ineffective removal methods. By removing the explicit statement of what not to do it is hoped that the possibility of people remembering bad behaviours as good behaviours will be avoided. In the event that some participants might wonder about different tick removal methods a general statement was included to say that the only safe removal method is the one described. This way there is clarity about what is safe and effective, but any mention of the non-recommended methods was avoided.

Strengths and weaknesses

The use of the read aloud protocol allowed for relatively quick feedback about intervention materials, both in terms of their readability and their ability to invoke or influence desired behaviour changes. The series of interviews conducted for this research provided detailed qualitative data as well as in depth insight into the thought processes surrounding potential behaviour change as a result of the intervention material. The use of the read aloud protocol also allows for a better understanding of participant mental models towards the topic.

In addition to the advantages listed above, there are also a number of drawbacks to the read aloud method. As with most qualitative research the sample size is low, restricting generalisability. A particular hurdle with regards to this protocol is that it can be difficult to get participants to verbalise their thoughts. People are not used to explaining their thought processes or reactions to much of the information they read so it can be challenging to get them to engage with this research method and it is possible that they did not give voice to all

thoughts elicited by the materials. Finally, this method is not ideal for assessing changes in behaviour. For this reason participants were asked a series of questions about their behaviour, both before and after having read the intervention. Although these responses cannot be quantified or generalised further, they do provide some indication of potential behaviour change.

A potential study limitation is that coding of the behaviour change techniques incorporated into the pre-existing leaflets was subjective. This is an inescapable limitation of coding, however a clear and specific coding frame exists for the coding of behaviour change techniques and studies have shown that there is high inter-coder reliability for the frame (Abraham & Michie, 2008). Consensus was sought from supervisors for the classification of any behaviour change techniques about which I was unsure.

Although every effort was made to make the three interventions as uniform as possible and only to change particular messages, there are likely still some small differences that could potentially confound any results. The length of each intervention is very similar as are the number and style of images, but the design process was really about ensuring that the two experimental interventions were tailored to what people wanted based on data from the qualitative interviews and quantitative survey. For example, interview participants talked about the need for more information about how to safely remove a tick, so this was addressed in the two experimental versions of the intervention. Any differences that do exist between the interventions are minor and should relate only to areas where text or messages needed to be tailored to fulfil specific needs. Furthermore, each of the intervention versions has been pilot tested using a read aloud protocol with members of the public to ensure that they meet the requirements of the study. As such, any potential confounding variables should have minimal impact on the overall study results.

During the qualitative interviews participants often explained that a determinant of whether or not they would engage in tick protective behaviours was their level of perceived likelihood of being bitten by a tick or of developing a tick-borne disease. The data from the quantitative online survey corroborated the qualitative data indicating that those participants who perceived the likelihood of bites or disease to be greater were more likely to report practicing protective behaviours. The intervention materials were designed to incorporate a greater amount of likelihood information about ticks and tick-borne disease in order to increase levels of perceived likelihood among participants and therefore hopefully increase practice of tick protective behaviour. However, beyond the number of confirmed laboratory cases of Lyme

disease occurring in the UK each year there is little information available about how prevalent ticks or Lyme disease are or how likely it is that someone is bitten and develops Lyme disease. This is difficult information to gather, but without it we are unable to provide the public with information that they want and which could alter their behaviour in a beneficial way.

A final potential limitation of the intervention materials is that they do not provide information about the treatment of Lyme disease. Although this information was available in the control intervention it was decided that it should be removed from the experimental interventions because the goal was to focus primarily on prevention and the importance of early recognition of both bites and disease. In addition, the quantitative survey data showed that perceptions about the effectiveness of Lyme disease treatment were not significant in the prediction of engagement in tick protective behaviours.

CHAPTER 5: PILOT RANDOMISED CONTROLLED TRIAL

Introduction

Qualitative and quantitative study designs are strong techniques for identifying and assessing correlates of behaviour, especially when used together. The data discussed in chapters 2 and 3 suggest that, in the UK, we could increase uptake of tick protective behaviours by providing people with more detailed information about disease likelihood and severity, by reducing reactions of disgust towards ticks and by increasing levels of confidence regarding ability to perform a tick check and ability to remove a tick if bitten. But to really understand causality, and to test whether such interventions work, we should ideally use a randomised controlled trial (RCT).

Chapter 1 found that RCTs in this area are rare. One reason why they are rare is that they can be difficult and expensive to set up. Prior to running them, therefore, it is important to pilot the basic concepts to identify problems and to demonstrate the practicability of a full-scale study. Pilot studies can be used to assess both the feasibility and the acceptability of the interventions, to assess the effectiveness of the study design and to facilitate the determination of effect sizes for use in sample size calculations (Feeley et al., 2009). In chapter 4 I piloted the interventions intended for use in an RCT. The full-scale RCT would aim to determine whether messaging about ticks and tick-borne disease is more effective at increasing the uptake of tick protective behaviour if it is based on conventional models of health psychology and/or disgust reduction.

In this chapter, I pilot tested the RCT itself, to test whether a full-scale RCT would be able to determine the effectiveness of each intervention at increasing the uptake of tick checking behaviour. For such an RCT various issues would need checking. Some of these are generic issues that apply to any RCT. For example, ensuring that the random allocation of participants to study conditions is maintained. Others are pragmatic issues that are more specific to this particular context. For example, while survey software is readily available and which would allow participants to complete follow-up questionnaires with ease, a recently discovered glitch in the software used by our team means that participants can, if they choose, use the back button on their browser to return to previous screens and review earlier questions and materials. Before devoting resources to correcting this issue, identifying if people actually take advantage of this glitch would be useful.

As part of this process, the aims of the pilot RCT were:

1. To identify likely levels of participant retention by detailing what percentage of participants completed both the initial and the follow-up questionnaires and whether this differed for each arm of the study
2. To determine whether the questionnaire scales were effective or whether they would be affected by floor or ceiling effects
3. To determine which intervention was most effective at increasing the uptake of tick checking behaviour, what the baseline tick checking rate might be in an RCT and hence what sample size would be required to detect specific increases in this rate
4. To gain quantitative feedback about the intervention materials in terms of usefulness, appropriateness and acceptability among participants
5. To determine whether the software used for the survey was appropriate and would be reliable for a full-scale RCT, particularly with regards to the randomisation of participants. In particular, to assess how many participants return to view the intervention after having moved on through the survey

Methods

Design

The design for this pilot RCT was intended to be as similar as possible to the planned full RCT. The pilot was conducted online using the programme Select Survey. Data collection occurred between 15 April 2013 and 5 June 2013 and consisted of two stages. The first stage required participants to complete questions before and immediately after seeing an intervention, while the second stage was a follow-up questionnaire approximately 6 weeks after the first stage. In this way I was able to obtain baseline (T1), immediately post-intervention (T2) and six week follow-up (T3) data. The questionnaires at T1 and T2 were completed in April so that the intervention materials would be seen by participants near the beginning of the British tick season. The follow-up period was set at six weeks in order to allow participants enough time to have the chance to engage in an outdoor activity during the interim period. The intervention materials had been pilot tested for readability and clarity as described in the previous chapter. Questions were then entered into the survey programme. Initially the programme did not have the capability to randomly allocate participants to an intervention

group, so an IT colleague within Public Health England was involved to solve this problem. A specific code was written to ensure that participants were randomly assigned to one of the three intervention groups, while still maintaining an even distribution of participants to each group. This was done by randomizing the first participant and then following a pattern to ensure each group had a similar number of participants. By using a participant's email address as a unique participant identifier, the code also ensured that if a participant closed their web browser mid-survey and began the survey again they would see the same version of the intervention. Participants were able to return to the intervention page; however they were not explicitly told that this was possible and the system allowed us to monitor how frequently this happened.

Ethics

Full ethical approval was obtained from King's College London (PNM 12/13-2).

Procedure

An email describing the study was sent to potential participants. Participants were told that the survey would involve answering questions about ticks and tick-borne disease in the UK and that they would also be contacted for a follow-up survey. They were assured that the data would be confidential and anonymous, that participation was voluntary and that they could withdraw from the survey at any point without having to provide a reason. As an incentive to increase participant numbers and to encourage completion of the study, a draw for a £200 prize was held. If people were interested in participating they were able to click on a web link to the survey which was included in the circular email and then complete the questions. The first survey question informed participants about the confidentiality of any data they provided and required them to indicate that they were happy to continue. All participants needed to provide their email address in order to be contactable for the prize draw and so that they could be sent the follow-up survey. Participants were informed that this would be kept completely confidential. All email addresses were deleted from the data sheet prior to analysis in order to make the data fully anonymous. The survey was set up so that each participant could only access and complete the survey a maximum of once. It was also necessary for participants to make a response to each question before being able to move forward through the survey. This was done in order to encourage survey completion and to minimise missing data.

Sample

Given that this was a pilot RCT, the main aim was not to detect differences between groups, but to establish an effect size to allow for a full-scale RCT sample size calculation. For this purpose it is recommended that there should be about 30 to 40 participants per group (Feeley et al., 2009). I also ran a power calculation based on one previous study (Daltroy et al., 2007) which compared the effects of a multi-modal tick intervention versus a multi-modal bike safety control condition. My primary outcome measure was the performance of tick checking behaviour and the study by Daltroy et al., (2007) found a significant effect of the tick intervention on tick checking behaviour with 51% of experimental participants reporting daily tick checking behaviour versus 37% of the control participants. No studies have been conducted in the UK to measure the effect size of tick interventions on the uptake of tick checking behaviour, but it is likely that American populations already have a higher baseline level for tick awareness and prevention behaviours, given their greater exposure to ticks and the higher prevalence of and political sensitivities surrounding Lyme disease. With this in mind, I set the target proportion of participants in the UK who engage in the behaviour at 40% when provided with the experimental interventions. Results from the web survey (chapter 3) indicated that currently only 24% of the study population engaged in tick checking behaviour. Using these proportions of 24% and 40%, then approximately 50 participants were required per condition in order to detect this as significant at $p < 0.05$ and with 80% power. I consulted with the Institute of Psychiatry Biostatistics Department concerning this calculation. Given this, I chose a target sample size of 50 people per intervention for this pilot study.

Participants

Participants were recruited from the Mind Search database. This is a database held by the Institute of Psychiatry, King's College London which includes contact details of people who are interested in being contacted by researchers who are in need of study participants. Participants were all contacted by email and were also given the option of forwarding the survey link on to friends, family or colleagues who they thought may be interested in taking part in the study.

In order to participate, respondents had to be at least 18 years of age, fluent in English and resident in London for at least the previous 2 years. In addition, one of the first questions on the survey asked respondents to indicate which of a variety of UK locations they had been to in the last 2 years in order to engage in rambling or walking (see appendix 24 for a full list of

survey questions). As with the survey detailed in chapter 3, these locations were all areas where ticks are known to be present. If they had not visited any of the locations listed in the past 2 years then they were considered ineligible for the study and were automatically redirected to the end of the survey.

Survey questions

Behavioural outcome variable questions

This section was largely similar to that used in the previous survey (as described in chapter 3), but this time participants were only asked one question about the primary outcome variable of tick checking behaviour. They were asked whether they checked their body for ticks after rambling or walking in potentially affected areas. The possible response options remained the same as the previous survey with: 'never (coded as 1)', 'almost never (2)', 'about half the time (3)', 'almost always (4)', or 'always (5)'. Those participants who indicated that they checked for ticks 'about half the time', 'almost always' or 'always' were asked about whether the check they engaged in involved different parts of the body or a variety of checking techniques. As before, possible response options were 'never (coded as a score of 1)', 'almost never (2)', 'about half the time (3)', 'almost always (4)', or 'always (5)'. In case their response was not shown in the available options, participants also had the choice to select 'other' and fill in their own response regarding how they perform a check. Participants who had responded that they either 'never' or 'almost never' engaged in checking for ticks after walking skipped the question about how a check was performed and moved to the questions regarding predictor variables.

Participants were also asked about their engagement in a series of secondary outcome variables "when rambling or walking in any of the UK locations listed above". These variables were the same six items which were included in the survey described in chapter 3. They included the protective behaviours of wearing long trousers, wearing light coloured trousers, tucking trousers into socks, sticking to clear pathways, using an insect repellent on clothes and using an insect repellent on skin. Response options used the same 'never' to 'always' scale as previously described.

At T3 only, participants were asked whether they had been walking in any of the listed UK locations during the time since the T1/T2 survey. If participants had been to one or more of the locations they were then asked whether they had engaged in any of the primary or

secondary outcome behaviours. Those who indicated that they 'never' or 'almost never' engaged in tick checking behaviour were directed to a question which asked them to explain why this was the case. They were able to select as many options as applied from a list that included, 'takes too much time', 'I forgot to do it', 'it was inconvenient', 'I didn't think I really needed to', 'I didn't know how to do a check', or 'no one I know did a check'. Participants then moved on to the predictor variable questions. If participants indicated that they had not been walking in one of the listed locations since the survey at T1/T2 they were directed to a question asking them to indicate how likely they were to engage in the primary and secondary outcome behaviours the next time they went to any of the locations. Similar to the previous scenario, participants who reported that they would 'never' or 'almost never' engage in tick checking behaviour were asked to indicate the reasons for this decision. Following this, participants moved on to answer the questions measuring predictor variables.

Predictor variable questions

The predictor variables for the pilot RCT were similar to those used in the survey as discussed in chapter 3; however there were some slight changes in order to refine the scales based on the previous survey results. Participants were asked a total of 21 questions concerning their perceptions of ticks and tick-borne disease. These questions were divided into six scales. A number of items were taken from the revised illness perceptions questionnaire (IPQ-R) (Moss-Morris et al., 2002) and adapted for use with this topic, while most items were devised to measure the predictor variables that emerged from the interviews described in chapter 2. The first scale was designed to assess perceptions among participants of ticks as creatures that evoke an emotion or reaction of disgust. This scale consisted of eight items, six of which were used in the earlier web survey and two that were added to the scale following that survey. All of the items were based on comments made during the public interviews, results of the web survey or the physiological symptoms of disgust (Kelly, 2011, p.16). Participants were asked to agree or disagree with the following eight statements: "ticks are disgusting", "having a tick biting me would be disgusting", "I would be disgusted if I had to remove a tick from myself", "having a tick biting me would make me feel nauseous", "I shudder when I think of ticks", "if I saw a tick near me I would feel a strong instinct to avoid it", "I would be too disgusted by a tick to remove it from myself" and "I would rather not know if I was bitten by a tick". The second and third scales dealt with self-efficacy and response efficacy respectively. The second scale for this study had three items that focused on self-efficacy, asking participants to agree or disagree with the statements, "I am confident that I could check my body for ticks after

walking or rambling, if I wanted to”, “If a tick bit me I am confident that I could remove it myself” and “I am confident that I could remember to check my body for ticks after walking or rambling, if I wanted to”. The third scale used one item to measure response efficacy, asking participants to agree or disagree with the statement, “Checking yourself for ticks is an effective way of reducing the chance of getting ill after walking or rambling”. The fourth scale remained the same as in the previous survey with two items that were adapted from the IPQ-R personal control subscale. These asked participants to agree or disagree with the statements, “Whether or not I get bitten by a tick when out walking in an affected area would depend on me” and “Nothing I do will affect whether or not I get bitten by a tick when out walking in an affected area”. The fifth scale was devised to measure perceived severity and adapted three items from the IPQ-R consequences subscale. Participants were asked to agree or disagree with the statements, “Getting bitten by a tick would have major consequences on my life”, “Developing Lyme disease would have major consequences on my life” and “Lyme disease would be a serious illness for me”. Finally, the sixth scale used four items to measure perceived likelihood of coming into contact with ticks, being bitten by ticks and developing a tick-borne disease. Three of these items were identical to those used in the previous survey and asked participants to agree or disagree with the statements, “I am likely to come into contact with ticks when out walking in an affected area”, “I am likely to be bitten by a tick when out walking in an affected area” and “If I was bitten by a tick I would develop Lyme disease”. One additional item was added to this scale asking participants to agree or disagree with the statement, “If I don’t take preventive action, then I am likely to develop Lyme disease”.

The above questions were all asked at T1, T2 and again at T3. During T2 one additional item was added which asked participants to agree or disagree with the statement, “Knowing more about ticks and tick-borne disease makes me want to avoid the outdoors”. In all other ways these questions were identical during each part of the pilot RCT, although their presentation was randomly re-ordered by the survey programme for each participant.

A five-point response format was used for all predictor variables, with participants asked whether they strongly agree (coded as a score of 5), agree (4), neither agree nor disagree (3), disagree (2) or strongly disagree (1) with each statement.

Knowledge and experience

Participants were asked to indicate which of a series of listed methods could be used to safely remove a tick. Participants had to select any correct options from a list of 7 potential removal strategies. They were allowed to select more than one option if they felt there was more than one correct answer and were also given the opportunity to write in an additional removal method if they felt that it had not been on the list, but should have been. Possible options were: pull off with tweezers (correct answer), pull off with your fingers (incorrect), cover with Vaseline (incorrect), cover with lighter fluid (incorrect), burn off with a cigarette (incorrect), wait for it to drop off by itself (incorrect), or cover it with salt (incorrect).

Demographic variables

Participants were asked to give their sex, age, pre-tax household income, highest educational qualification and ethnicity.

Analyses

All analysis was done using IBM SPSS Statistics 19. All incomplete surveys were removed from the dataset prior to analysis. This included surveys which a participant had started but not finished as well as surveys where the participant was found to be ineligible to proceed with the full survey.

Any free-text responses relating to safe and effective tick removal strategies were assessed for correctness and coded accordingly. For instance, a participant may have suggested that correct removal should be done with a specific, commercially-available tick removal device. This would have been considered a correct answer.

The first stage of analysis involved assessing the reliability of the predictor variable scales at baseline measurement using Cronbach's alphas and Pearson correlations.

Recoding was used to simplify the analysis of the demographic variables including ethnicity, education and income. Ethnicity was recoded as 'white', 'any other ethnic background' or 'prefer not to say'. Education was recoded as 'anything up to and including A-levels or equivalent', 'Bachelor degree or equivalent or higher' or 'other/no formal qualifications/still studying'. Finally, income was recoded as '< £10,000 to £30,000', '£30,000 to £50,000',

‘£50,000 or over’ or ‘prefer not to say’. Following this I tested the difference between intervention conditions at T1 in terms of demographics using chi-squared tests.

The majority of participants selected ‘never’ or ‘almost never’ for the main outcome variable of tick checking, so this variable was recoded and dichotomised into those who checked ‘never (0)’ or ‘almost never (0)’ and those who checked ‘about half the time (1)’, ‘almost always (1)’ and ‘always (1)’. I tested the difference between intervention conditions at T1, T2 and T3 in terms of the primary outcome of tick checking using separate binary logistic regressions. This was also done for the secondary outcome measures.

Scores for all predictor variables were tested for normality in order to determine the appropriate parametric or non-parametric analyses. Results from Kolmogorov-Smirnov tests for normality showed that the data for each of the 21 variables (6 scales and 3 stand-alone items) were not normally distributed. I tested the difference between intervention conditions at T1, T2 and T3 in terms of predictor variables using Kruskal-Wallis and Mann-Whitney U tests.

The difference in drop-out rates between the arms of the experiment were tested using Fisher’s exact test.

The sample size calculation for the full RCT was calculated using nQuery Advisor 4.0.

Results

Aim 1: Participant retention

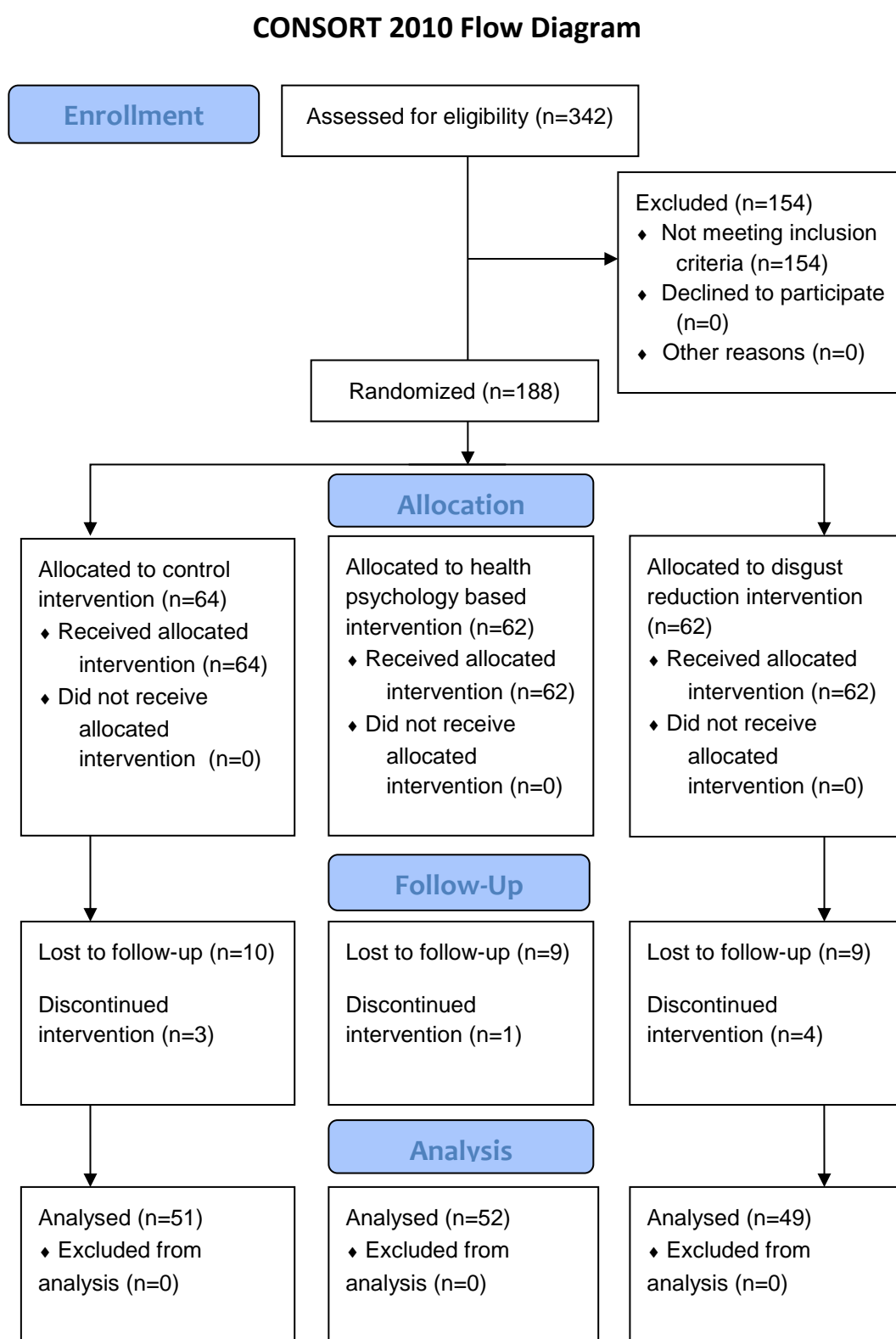
The initial survey was opened to the public on 15 April 2013 and closed on 29 April 2013. The survey details and web link were sent by email to all 900 members on the Mind Search database. During the time that the survey was live, 514 people clicked on the web link, 340 of whom provided consent and an email address. Of these people, 65 were excluded because they had not lived in London for at least the past 2 years and a further 89 were excluded because they had not been to any of the tick affected locations listed. This left 188 participants who were assigned to one of the three intervention groups. Eight participants failed to complete the survey and the majority of these drop-outs occurred on or soon after the page showing the intervention material. Of these drop-outs, 4 were from the disgust

reduction group, 3 were from the control group and 1 was from the group with the intervention based on conventional models within health psychology. This left a total of 180 participants overall with 61 in the control group, 61 in the health psychology based group and 58 in the disgust reduction group after the first stage of data collection.

All 180 participants were sent an email on 29 May 2013 to invite them to take part in a follow-up survey. By 2 June 2013 a total of 135 participants (75.0%) had completed the survey. A reminder email was sent on 3 June 2013 to the 45 participants who had not yet completed the survey. This reminder resulted in 17 more participants completing the survey, which meant that a total of 152 participants (84.4%) took part in the entire study. There were 51 participants in the control group, 52 participants in the health psychology based group and 49 participants in the disgust reduction group.

Using the number of participants who were randomized as the denominator for each of the intervention groups, the control group lost 13 (20%) participants, the health psychology based group lost 10 (16%) and the disgust reduction group lost 13 (21%). Fisher's exact test found no significant difference in participant drop-out rates between groups ($p = 0.76$). See the CONSORT 2010 Flow Diagram in figure 5.1 for full details of participant drop-out.

Figure 5.1 Participant drop-out by group



Aim 2: Effectiveness of variables and scales

Factor analysis was initially considered as a data reduction technique and as a method to determine the robustness of the variable scales; however it was not used for three reasons. First, the sample size of 152 participants was judged to be too low to ensure the reliability of the analysis. Although guidelines regarding the necessary sample size for factor analysis have become more relaxed, a sample size of 150 is still considered small and there is the tendency for correlation coefficients to become less reliable and vary between samples (Pallant, 2010). Secondly, factors with three or fewer items are generally considered to be weak and unstable (Costello & Osborne, 2005). In this study all of the variables except disgust were made up of three items or fewer so this was not ideal. Finally, given that this was a pilot RCT, the formation of strong predictor variable scales was considered secondary to the ability to change the main outcome variable of tick checking.

Instead of using factor analysis, variable scale strength and reliability was assessed using Cronbach's alphas and correlations. Only 2 of the 5 scales had a Cronbach's alpha score of greater than 0.7. These were disgust ($\alpha = 0.87$) and perceived severity ($\alpha = 0.86$). The remaining scales were tested for inter-item correlations and all were significantly correlated at the 0.05 level or 0.01 level. Self-efficacy and perceived control remained the same with 3 and 2 items respectively, but perceived likelihood was divided into two separate scales. These were 2 items that formed a 'perceived likelihood of being bitten' scale and 2 items that formed a 'perceived likelihood of contracting Lyme disease' scale. Mean scores were taken for each of the scales, while the remaining 3 items were kept separate.

Given that this was a pilot study, associations were not analysed between each of the primary and secondary outcome variables and the predictor variables.

Aim 3: Intervention effectiveness and sample size calculation

Participant demographics

A total of 111 participants (73%) were female. All participants were at least 18 years of age, with 75% aged 44 or younger. Participant household income was fairly evenly distributed across the income categories. Apart from the 14% of participants who reported that they would prefer not to provide their income details, the remaining income categories had participant response rates of between 8% and 17%. The majority of participants reported their highest educational qualifications as either a bachelor degree or equivalent (40% of participants), or a masters or PhD (40% of participants). The vast majority of participants

indicated that they were either 'White-British' (62%), 'White-Irish' (7%), or 'White-Any other background' (17%). Answers were therefore recoded either as 'White', 'Any other background' and 'Prefer not to answer'.

The breakdown of participant demographics remained largely similar across all three study groups and Chi-square tests for independence indicated no significant associations between any demographic variable and intervention group. Full details can be seen in table 5.1.

Table 5.1 Participant demographics by group

	Response (%)				
Demographic Variable	Control Group (n=51)	Health Psychology based Group (n=52)	Disgust Reduction Group (n=49)	χ^2	p
Gender				0.15	0.93
Male	13 (26%)	15 (29%)	13 (27%)		
Female	38 (74%)	37 (71%)	36 (73%)		
Age				1.46	0.99
18-24	10 (20%)	10 (19%)	11 (23%)		
25-34	20 (39%)	23 (44%)	22 (45%)		
35-44	6 (12%)	7 (13%)	6 (12%)		
45-54	7 (14%)	5 (10%)	4 (8%)		
55+	8 (15%)	7 (14%)	6 (12%)		
Income				5.71	0.46
Up to £30,000	20 (39%)	22 (43%)	23 (47%)		
From £30,000 and £50,000	14 (28%)	11 (21%)	6 (12%)		
Over £50,000	13 (25%)	10 (19%)	12 (25%)		
Prefer not to say	4 (8%)	9 (17%)	8 (16%)		
Education				0.19	0.91
Up to A-level or equivalent (=NVQ3	7 (14%)	5 (10%)	7 (14%)		
Bachelors/Master/PhD or equivalent	40 (78%)	41 (79%)	40 (82%)		
Other/no qualification/still studying	4 (8%)	6 (11%)	2 (4%)		
Ethnicity				2.00	0.37
White (British, Irish, any other White background)	45 (88%)	42 (80%)	44 (90%)		
Any other ethnicity*	6 (12%)	7 (14%)	4 (8%)		
Prefer not to say	0 (0%)	3 (6%)	1 (2%)		

*includes the following ethnicity categories: Asian or Asian British - Indian, Pakistani, Bangladeshi, Any other Asian background; Black or Black British – Caribbean, African, Any other Black background; Mixed – White and Black Caribbean, White and Black African, White and Asian, Any other mixed background; Chinese or other ethnic group – Chinese, Any other background

Uptake of tick checking behaviour

At T1, a total of 25 participants (16%) reported that they had performed a tick check 'at least half the time' or more. Across intervention groups, tick checking behaviour was reported 'at least half the time' by 10 participants (19.6%) in the control group, 9 participants (17.3%) in the health psychology based group and 6 participants (12.2%) in the disgust reduction group. Binary logistic regression revealed no statistically significant difference in tick checking behaviour across the three groups at T1 (see table 5.2).

At T2 (immediately post-intervention), the results were very different. A total of 138 (91%) participants (49 control; 47 health psychology based; 42 disgust reduction) reported that in the future they intended to check for ticks 'at least half the time'. Binary logistic regression revealed no statistically significant difference in tick checking behaviour across the three groups at T2 (table 5.2).

At T3 (approximately 6 weeks post-intervention), participants were asked whether they had engaged in any rambling or walking in any of the tick affected areas of the UK that were listed. Of the 152 total participants, 48 (32%) had been to one of the locations since the previous survey at T2, of which 16 (31.4%) were in the control group, 17 (32.7%) were in the health psychology based group and 15 (30.6%) were in the disgust reduction group. Each of these 48 participants were then asked whether they had engaged in tick checking behaviour after visiting the location and 30 (63%) participants (7 (23.3%) control; 16 (53.3%) health psychology based; 7 (23.3%) disgust reduction) indicated that they had done so 'at least half the time' or more. Binary logistic regression (table 5.2) revealed that, among participants who had been walking in a tick affected location, those in the control group and the disgust reduction group were significantly less likely to report engaging in tick checking behaviour 'at least half the time' compared to participants in the conventional health psychology based group.

The 104 (68.4%) participants (35 (68.6%) control; 35 (67.3%) health psychology based; 34 (69.4%) disgust reduction) who had not been to a tick endemic area during the follow-up period were asked to indicate their intention to engage in tick checking behaviour the next time they did venture to one of the listed areas. A total of 87 (84%) participants (30 (58.8%) control; 27 (51.9%) health psychology based; 30 (61.2%) disgust reduction) reported that they would check for ticks 'about half the time', 'almost always' or 'always' in the future. Among those participants who had not been walking since T2, no statistically significant differences

were revealed in intended levels of tick checking behaviour across the three intervention groups.

Full details of these tests can be seen in table 5.2.

Table 5.2 Tick checking behaviour by intervention group at T1, T2 and T3

Intervention group by time point	No (%)	No (%) intending to check/checking for ticks at least half the time	<i>p</i>	Odds ratio (95% CI)
T1				
Control	51 (34.0)	10 (19.6)	0.76	1.17 (0.43 to 3.16)
Disgust Reduction	49 (32.0)	6 (12.2)	0.48	0.67 (0.22 to 3.16)
Health Psychology	52 (34.0)	9 (17.3)	0.60	Ref
T2				
Control	51 (34.0)	49 (96.0)	0.27	2.61 (0.48 to 14.10)
Disgust Reduction	49 (32.0)	42 (85.7)	0.47	0.64 (0.19 to 2.16)
Health Psychology	52 (34.0)	47 (90.4)	0.23	Ref
T3 (behaviour)				
Control	16 (34.0)	7 (43.8)	0.008	0.05 (0.005 to 0.46)
Disgust Reduction	15 (31.0)	7 (46.7)	0.01	0.06 (0.01 to 0.52)
Health Psychology	17 (35.0)	16 (94.0)	0.03	Ref
T3 (intention)				
Control	35 (34.0)	30 (85.7)	0.36	1.78 (0.52 to 6.10)
Disgust Reduction	34 (32.0)	30 (88.2)	0.23	2.22 (0.60 to 8.22)
Health Psychology	35 (34.0)	27 (77.1)	0.43	Ref

The T3 rate from the control group was used to determine the sample size estimates that are required to detect 10, 20, 30, 40 and 50 percent increases in tick checking behaviour. These sample sizes are shown in table 5.3 and are for use in a full scale RCT with 2 groups (all have 80% power and 0.05 two-sided significance level). This data can help an organisation such as Public Health England to determine the effect size that they would like to detect and the sample size that would be necessary to do this.

Table 5.3 Sample sizes by intervention effect size compared to control

Increase (%)	Sample Size Per Study Arm for Analysis (N)	And therefore sample you need to invite
10	5481	66221
20	1377	16558
30	630	7610
40	363	4389
50	238	2875

Table 5.4 shows how the drop out rates for each stage of the pilot RCT (see figure 5.1) affects our ability to include the data on a single participant who had been walking during the study. For each of these participants in the analysis, we needed to invite 18.6 people to take part.

Table 5.4 Full scale RCT recruitment calculations

RCT Stage	Sample Size
Invitation to take part in study	1786
Click the web link	1018
Eligible for study	672
Randomised to intervention group	370
Complete entire study	300
Have been walking during study	96

Assessment of interventions (predictor variables)

Kruskal-Wallis tests revealed three statistically significant differences in predictor variables across the intervention groups. These significant differences were in the perceived likelihood of contracting Lyme disease across groups at T1 and in reports that checking for ticks is an effective way of reducing the chance of becoming ill after walking across groups at both T2 and T3. Full details of the test results are available in table 5.5. In order to assess which of the groups were statistically significantly different from one another I conducted follow-up Mann-Whitney U tests. This revealed that participants in the conventional health psychology intervention group were significantly more likely to perceive the likelihood of contracting Lyme disease after walking in an affected area as high at T1 compared to participants in the disgust reduction group at T1 ($p = 0.02$, $r = 0.2$). Testing also revealed that at T2, participants in the conventional health psychology based intervention group were more likely to report that they felt tick checking would be effective compared to both the disgust reduction group ($p = 0.02$, $r = 0.2$) and the control group ($p = 0.03$, $r = 0.2$). At T3, tests again revealed that participants in the conventional health psychology based group were more likely to report that they felt tick checking would be effective compared to both the disgust reduction group ($p = 0.02$, $r = 0.2$) and the control group ($p = 0.02$, $r = 0.2$).

Table 5.5 Difference in intervention conditions at T1, T2 and T3 based on predictor variables

	T1		T2		T3	
Predictor Variable (example statement)	p	χ^2	p	χ^2	p	χ^2
Disgust (Ticks are disgusting)	0.54	1.25	0.74	0.60	0.93	0.15
Perceived severity (Lyme disease would be a serious illness for me)	0.52	1.32	0.76	0.54	0.26	2.72
Self-efficacy (If a tick bit me I am confident I could remove it myself)	0.12	4.29	0.45	1.61	0.64	0.90
Perceived control (Whether or not I get bitten by a tick when out walking in an affected area would depend on me)	0.77	0.51	0.39	1.87	0.86	0.29
Perceived likelihood of being bitten (I am likely to be bitten by a tick when walking in an affected area)	0.08	4.96	0.70	0.71	0.31	2.32
Perceived likelihood of contracting Lyme disease (If I was bitten by a tick I would develop Lyme disease)	0.04	6.47	0.79	0.48	0.98	0.04
I would rather not know if I was bitten by a tick	0.46	1.54	0.14	3.99	0.44	1.63
Checking for ticks is an effective way of reducing the chance of getting ill after walking or rambling	0.61	1.00	0.03	6.97	0.02	7.48
Getting bitten by a tick would have major consequences on my life	0.45	1.62	0.74	0.61	0.48	1.45

Assessment of interventions (secondary outcomes)

Binary logistic regressions revealed no statistically significant difference in any secondary outcome behaviours across the three groups at T1, T2 or T3. Full details of scores for each behaviour can be seen in tables 5.6 through 5.11.

Table 5.6 Wearing long trousers by intervention group at T1, T2 and T3

Intervention group by time point	No (%)	No (%) intending to wear/wearing long trousers at least half the time when walking	<i>p</i>	Odds ratio (95% CI)
T1				
Control	51 (34.0)	48 (94.1)	0.72	1.33 (0.28 to 6.28)
Disgust Reduction	49 (32.0)	45 (91.8)	0.93	0.94 (0.22 to 3.97)
Health Psychology	52 (34.0)	48 (92.3)	0.90	Ref
T2				
Control	51 (34.0)	50 (98.0)	0.99	0.00 (0.00 to -)
Disgust Reduction	49 (32.0)	49 (100.0)	1.00	0.72 (0.00 to -)
Health Psychology	52 (34.0)	52 (100.0)	1.00	Ref
T3 (behaviour)				
Control	16 (34.0)	16 (100.0)	1.00	1.00 (0.00 to -)
Disgust Reduction	15 (31.0)	13 (86.7)	1.00	0.06 (0.00 to -)
Health Psychology	17 (35.0)	17 (100.0)	0.99	Ref
T3 (intention)				
Control	35 (34.0)	33 (94.3)	0.56	0.49 (0.04 to 5.61)
Disgust Reduction	34 (32.0)	33 (97.1)	0.98	0.97 (0.06 to 16.17)
Health Psychology	35 (34.0)	34 (97.1)	0.79	Ref

Table 5.7 Wearing light coloured trousers by intervention group at T1, T2 and T3

Intervention group by time point	No (%)	No (%) intending to wear/wearing light colour trousers at least half the time when walking	<i>p</i>	Odds ratio (95% CI)
T1				
Control	51 (34.0)	18 (35.3)	0.60	0.81 (0.36 to 1.79)
Disgust Reduction	49 (32.0)	16 (32.7)	0.42	0.72 (0.32 to 1.62)
Health Psychology	52 (34.0)	21 (40.4)	0.71	Ref
T2				
Control	51 (34.0)	37 (72.5)	0.95	0.97 (0.41 to 2.32)
Disgust Reduction	49 (32.0)	37 (75.5)	0.78	0.64 (0.47 to 2.79)
Health Psychology	52 (34.0)	38 (73.1)	0.94	Ref
T3 (behaviour)				
Control	16 (34.0)	9 (56.3)	0.62	0.70 (0.17 to 2.85)
Disgust Reduction	15 (31.0)	6 (40.0)	0.17	0.36 (0.09 to 1.53)
Health Psychology	17 (35.0)	11 (64.7)	0.38	Ref
T3 (intention)				
Control	35 (34.0)	24 (68.6)	0.62	1.29 (0.48 to 3.47)
Disgust Reduction	34 (32.0)	18 (52.9)	0.41	0.67 (0.25 to 1.74)
Health Psychology	35 (34.0)	22 (62.9)	0.41	Ref

Table 5.8 Tucking trousers into socks by intervention group at T1, T2 and T3

Intervention group by time point	No (%)	No (%) intending to tuck/tucking trousers into socks at least half the time when walking	<i>p</i>	Odds ratio (95% CI)
T1				
Control	51 (34.0)	12 (23.5)	0.30	1.69 (0.63 to 4.57)
Disgust Reduction	49 (32.0)	7 (14.3)	0.88	0.92 (0.31 to 2.75)
Health Psychology	52 (34.0)	8 (15.4)	0.42	Ref
T2				
Control	51 (34.0)	37 (72.5)	0.61	0.79 (0.33 to 1.93)
Disgust Reduction	49 (32.0)	30 (61.2)	0.09	0.47 (0.20 to 1.12)
Health Psychology	52 (34.0)	40 (76.9)	0.21	Ref
T3 (behaviour)				
Control	16 (34.0)	5 (31.3)	0.55	0.65 (0.16 to 2.72)
Disgust Reduction	15 (31.0)	6 (40.0)	0.95	0.95 (0.23 to 3.92)
Health Psychology	17 (35.0)	7 (41.2)	0.82	Ref
T3 (intention)				
Control	35 (34.0)	21 (60.0)	0.81	0.89 (0.34 to 2.32)
Disgust Reduction	34 (32.0)	16 (47.1)	0.19	0.53 (0.20 to 1.37)
Health Psychology	35 (34.0)	22 (62.9)	0.38	Ref

Table 5.9 Sticking to clear pathways by intervention group at T1, T2 and T3

Intervention group by time point	No (%)	No (%) intending to stick/sticking to clear pathways at least half the time when walking	<i>p</i>	Odds ratio (95% CI)
T1				
Control	51 (34.0)	44 (86.3)	0.19	0.39 (0.09 to 1.58)
Disgust Reduction	49 (32.0)	45 (91.8)	0.64	0.69 (0.15 to 3.25)
Health Psychology	52 (34.0)	49 (94.2)	0.38	Ref
T2				
Control	51 (34.0)	47 (92.2)	0.98	0.98 (0.23 to 4.15)
Disgust Reduction	49 (32.0)	48 (98.0)	0.22	4.00 (0.43 to 37.11)
Health Psychology	52 (34.0)	48 (92.3)	0.43	Ref
T3 (behaviour)				
Control	16 (34.0)	15 (93.8)	0.97	0.94 (0.05 to 16.37)
Disgust Reduction	15 (31.0)	13 (86.7)	0.48	0.06 (0.03 to 5.00)
Health Psychology	17 (35.0)	16 (94.1)	0.71	Ref
T3 (intention)				
Control	35 (34.0)	34 (97.1)	0.33	3.19 (0.32 to 32.24)
Disgust Reduction	34 (32.0)	33 (97.1)	0.34	3.09 (0.31 to 31.32)
Health Psychology	35 (34.0)	32 (91.4)	0.48	Ref

Table 5.10 Using repellent on clothes by intervention group at T1, T2 and T3

Intervention group by time point	No (%)	No (%) intending to use/using repellent on clothes at least half the time when walking	<i>p</i>	Odds ratio (95% CI)
T1				
Control	51 (34.0)	10 (19.6)	0.26	1.87 (0.63 to 5.60)
Disgust Reduction	49 (32.0)	4 (8.2)	0.57	0.68 (0.18 to 2.58)
Health Psychology	52 (34.0)	6 (11.5)	0.23	Ref
T2				
Control	51 (34.0)	33 (64.7)	0.78	0.89 (0.39 to 2.01)
Disgust Reduction	49 (32.0)	25 (51.0)	0.09	0.50 (0.22 to 1.13)
Health Psychology	52 (34.0)	35 (67.3)	0.20	Ref
T3 (behaviour)				
Control	16 (34.0)	2 (12.5)	0.08	0.20 (0.04 to 1.20)
Disgust Reduction	15 (31.0)	5 (33.3)	0.65	0.71 (0.17 to 3.03)
Health Psychology	17 (35.0)	7 (41.2)	0.21	Ref
T3 (intention)				
Control	35 (34.0)	15 (42.9)	0.81	0.89 (0.35 to 2.29)
Disgust Reduction	34 (32.0)	18 (52.9)	0.55	1.34 (0.52 to 3.44)
Health Psychology	35 (34.0)	16 (45.7)	0.69	Ref

Table 5.11 Using repellent on skin by intervention group at T1, T2 and T3

Intervention group by time point	No (%)	No (%) intending to use/using repellent on skin at least half the time when walking	<i>p</i>	Odds ratio (95% CI)
T1				
Control	51 (34.0)	19 (37.3)	0.18	1.78 (0.76 to 4.15)
Disgust Reduction	49 (32.0)	18 (36.7)	0.20	1.74 (0.74 to 4.10)
Health Psychology	52 (34.0)	13 (25.0)	0.33	Ref
T2				
Control	51 (34.0)	40 (78.4)	0.85	1.09 (0.43 to 2.76)
Disgust Reduction	49 (32.0)	33 (67.3)	0.28	0.62 (0.26 to 1.49)
Health Psychology	52 (34.0)	40 (76.9)	0.39	Ref
T3 (behaviour)				
Control	16 (34.0)	3 (18.8)	0.48	0.55 (0.12 to 2.83)
Disgust Reduction	15 (31.0)	4 (26.7)	0.86	0.87 (0.19 to 4.11)
Health Psychology	17 (35.0)	5 (29.4)	0.77	Ref
T3 (intention)				
Control	35 (34.0)	25 (71.4)	0.22	1.88 (0.70 to 5.06)
Disgust Reduction	34 (32.0)	21 (61.8)	0.70	1.21 (0.46 to 3.17)
Health Psychology	35 (34.0)	20 (57.1)	0.45	Ref

Aim 4: Intervention feedback

At T2, after having seen a version of the intervention, each participant was asked to provide feedback about the intervention based on agreement with a variety of statements. Overall, participants seemed to find the interventions both reassuring and useful. Full response details can be seen in figures 5.2 to 5.7.

Figure 5.2 Based on data from 152 total respondents and divided by group

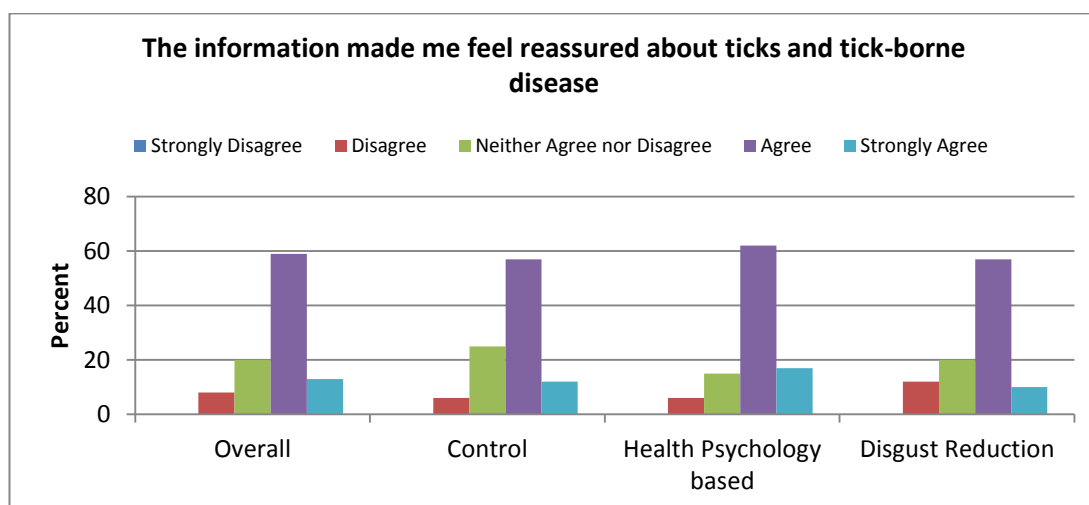


Figure 5.3 Based on data from 152 total respondents and divided by group

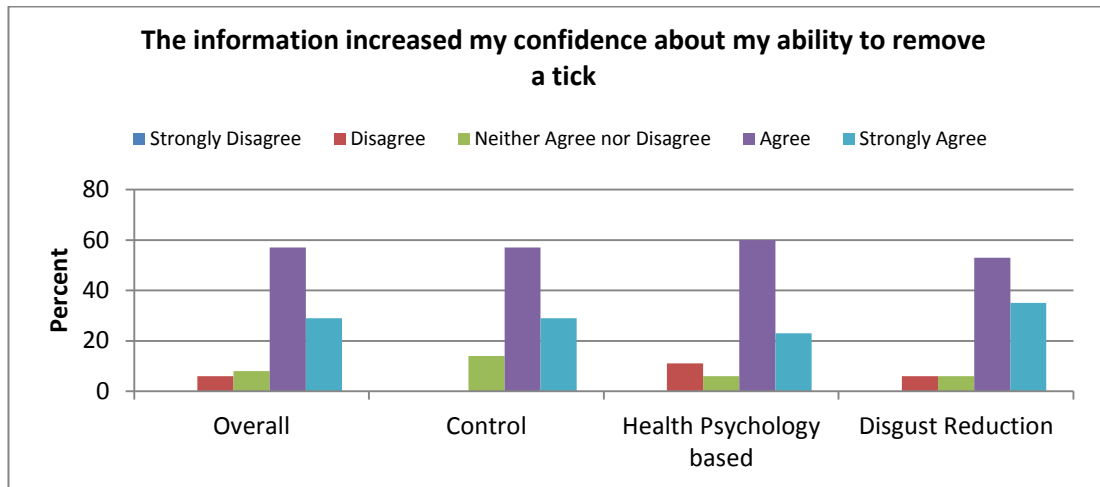


Figure 5.4 Based on data from 152 total respondents and divided by group

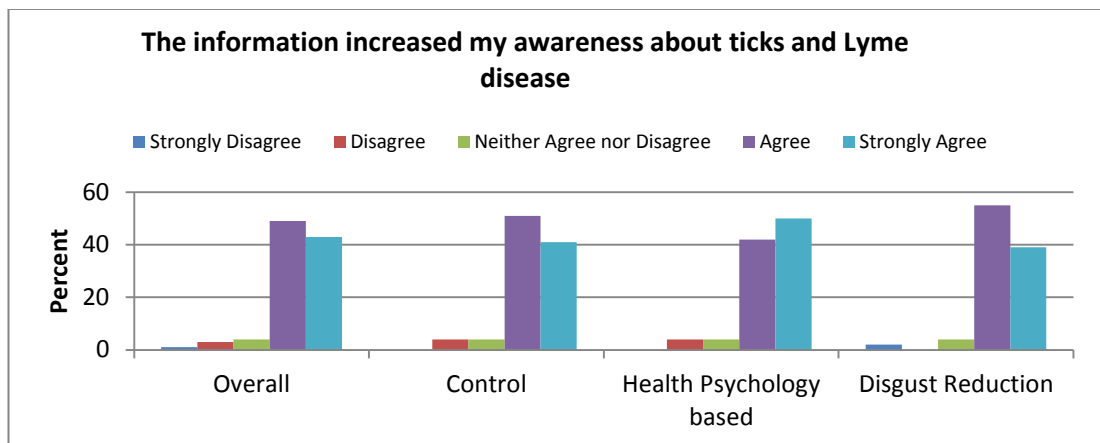


Figure 5.5 Based on data from 152 total respondents and divided by group

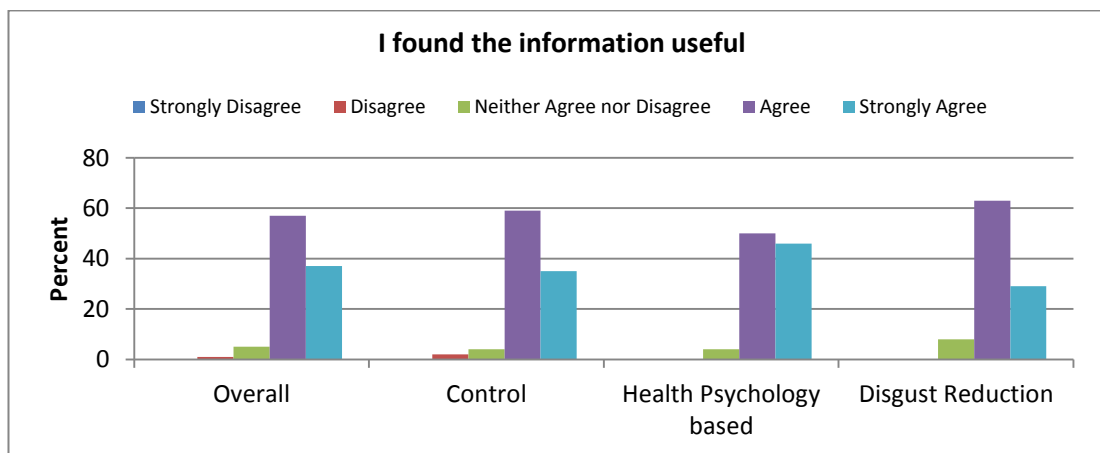


Figure 5.6 Based on data from 152 total respondents and divided by group

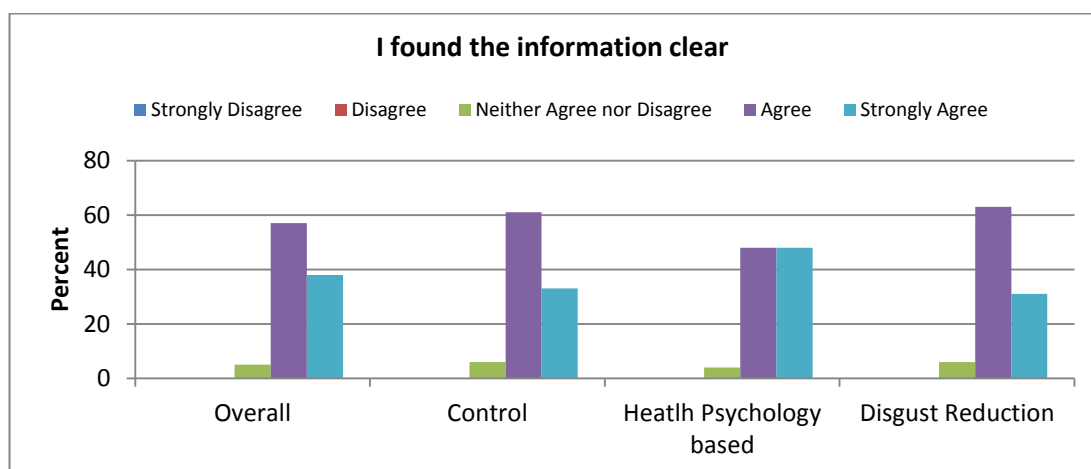
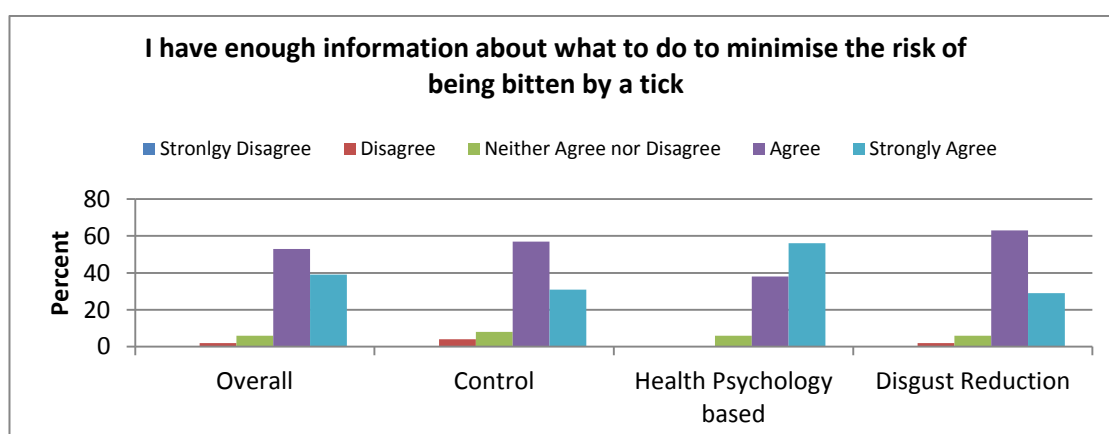


Figure 5.7 Based on data from 152 total respondents and divided by group



Kruskal-Wallis Tests indicated that only the intervention feedback variable 'I have enough information about what to do to minimise the risk of being bitten by a tick' had a significant association with the intervention groups (see table 5.12). Mann-Whitney U Tests were used to determine which of the intervention groups was significantly different from the others. These tests revealed that participants in the health psychology based group ($Md = 5$, $n = 52$) were significantly more likely than those in the control group ($Md = 4$, $n = 51$) to report that they felt they had enough information about how to minimise the risk of tick bites ($U = 983$, $z = -2.52$, $p = 0.012$, $r = 0.25$). There was also a significant difference which showed that participants in the health psychology based group were more likely than those in the disgust reduction group ($Md = 4$, $n = 49$) to report having enough information ($U = 932.50$, $z = -2.60$, $p = 0.009$, $r = 0.26$).

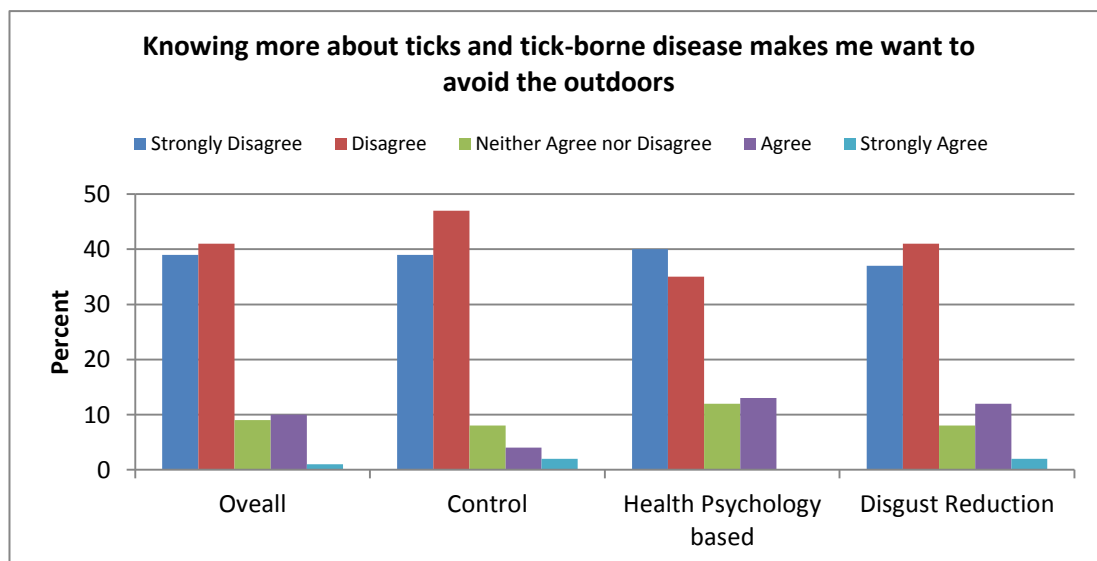
There was no significant difference between the control group and the disgust reduction group.

Table 5.12 Based on data from 152 total respondents and divided by group

Intervention Feedback Variable	No (%) responded 'agree' or 'strongly agree'	X ²	p
The information made me feel reassured about ticks and tick-borne disease	109 (71.7)	2.68	0.26
The information increased my confidence about my ability to remove a tick	130 (85.5)	1.95	0.38
The information increased my awareness about ticks and Lyme disease	141 (92.8)	1.02	0.60
I found the information useful	143 (94.1)	3.72	0.16
I found the information clear	144 (94.7)	3.76	0.15
I have enough information about what to do to minimise the risk of being bitten by a tick	139 (91.4)	8.89	0.01

After seeing a version of the intervention, all participants were also asked whether knowing more about ticks and tick-borne disease made them want to avoid the outdoors. The majority of participants, 121 (80%), indicated 'disagreed' or 'strongly disagreed' with the suggestion that they would avoid the outdoors. Full details can be seen in figure 5.8. Kruskal-Wallis Tests revealed that there was no statistically significant difference in avoidance of the outdoors across the 3 intervention groups.

Figure 5.8 Based on data from 152 total respondents and divided by group



Aim 5: Test the effectiveness of Select Survey for delivering the pilot RCT

Although Select Survey was not originally capable of participant randomisation to different intervention conditions, this was overcome with the help and expertise of a colleague in IT. During the pilot RCT there were no problems encountered with either the randomisation of participants or any of the functionality of the survey programme.

Data was also captured to assess whether participants returned to view the intervention leaflet as well as the average amount of time spent on the intervention page by group. Details can be seen in table 5.13. The average time spent on each leaflet is based only on the first viewing and does not take into account time spent by those who returned to review the leaflets.

Table 5.13 Based on data from 152 total respondents and divided by group

	Control	Health Psychology based	Disgust Reduction
Returned to leaflet	21 (41.2%)	15 (28.8%)	12 (25.5%)
Average time spent on leaflet (with 15 second margin of error)	5 minutes	3 minutes 10 seconds	2 minutes 20 seconds

Discussion

This pilot study produced a number of interesting results which have a series of implications for tick and tick-borne disease communication materials. In addition, several methodological limitations were identified that if considered during the development of a full-scale RCT should result in a successful study.

One of the most interesting results was that participants in the control group and the disgust reduction group were significantly less likely to have reported performing a tick check during the study follow-up period. Although it was hoped that the intervention based on conventional theories of health psychology would result in an increase in tick checking behaviour, there was also some expectation that the disgust reduction intervention would also find this effect, especially as it also incorporated psychological theory into its design. The elements that made the disgust reduction intervention different from the health psychology based intervention were the inclusion of statements that were designed to reassure participants about their ability to perform a tick check and to safely remove a tick. Perhaps

this reassurance eroded participant perceptions of severity to a point that they no longer had the impetus to engage in tick checking behaviour. Interestingly there was no difference between intervention groups on the uptake of tick checking behaviour seen immediately after the intervention at T2, or among participants who had not been walking during the follow-up period. Perhaps this is an indication that it is important to get a direct measure of behaviour change rather than basing intervention effectiveness on an intention to change behaviour.

Another possibility is that participants who saw the disgust reduction intervention may have found the messaging to be rather patronising. During the read aloud pilot testing of the intervention materials one participant did suggest that they found the disgust reduction messages to be suitable for children or younger adults who may need more guidance, but that adults might see the messages as too obvious or condescending. If participants did react in this way then they may have tuned out the messages and this could potentially explain why the disgust reduction intervention appears to be more harmful than beneficial to the uptake of tick protective behaviours. If this is the case then it raises some questions about whether this is a specific reaction with regards to disgust and ticks, or whether it could be found between disgust and other health behaviours. To date, studies that have investigated the use of disgust as a driver of health behaviour have compared it to methods within health psychology, as in the study of hand-washing behaviour by Judah et al. (2009), but have not combined the two. Perhaps it is this combination of health psychology based and disgust based messaging that has mitigated the effect of the intervention. For example, maybe disgust was reduced among participants who saw that intervention, but the inclusion of these messages meant that other barriers to behaviour remained in place.

It is also worth considering that the changes in tick checking behaviour may be a result of the novel subject matter rather than the intervention materials. The majority of participants did not have a great deal of knowledge about ticks or tick-borne disease at T1 and it may be that the topic increased their interest because it was something unfamiliar. Therefore, behaviour change techniques such as the provision of general information on the health-behaviour link as would be found in any intervention may be picked up more readily by participants than if they had been applied to a less novel topic. To address this possibility it would be interesting for a full-scale study to include an arm that contained no intervention material.

Limitations and strengths

Unfortunately, only 48 participants (32%) reported that they had been to at least one of the locations where ticks are known to be present during the follow-up period, potentially because the follow-up period was not long enough. This meant that the majority of participants were reporting behavioural intentions to check for ticks at follow-up, rather than actual behavioural engagement. Although research has shown that intentions to perform a behaviour have a reliable association with future behaviour change, this has a small to medium effect size and obtaining a measure of behavioural engagement would still be preferable (Sheeran, Milne, Webb & Gollwitzer, 2005). A review of health behaviours by Sheeran (2002) looked at the proportion of people with positive intentions who subsequently did not perform a behaviour compared to those with negative intentions who did engage in the behaviour. Findings indicated that just about half of the people with positive intentions to engage in health behaviours actually translated their intentions into action (Sheeran, 2002). This highlights the importance of being able to obtain and analyse information about direct behavioural engagement. Perhaps a future study with a longer follow-up period, or a series of follow-up periods, could better examine some of the differences between those people who have engaged in tick checking behaviour and those who have not. Alternatively, a larger study could also examine these differences.

It may also be that because of the relatively short follow-up period, those participants who did go walking were people who are keen outdoors people rather than people who occasionally engage in outdoor activities, but not on a regular basis. If this was the case then the intervention materials may have been of more direct relevance and interest to those people who reported going to one of the locations during the follow-up period and they may have spent a greater amount of time reading and later recalling the information. The target population were members of the public who lived in an urban area and engaged in outdoor activities, meaning that they would be at risk of tick bites, but less aware of this risk compared to people living in a tick endemic area. Therefore, if participants who were keen outdoors people were more likely to read and recall the information then this may not be a representative sample of those that I was intending to target.

As with the survey described in chapter 3, the demographics showed that participants tended to be young, well-educated, female and White. Issues with generalisability based on these demographics were discussed in chapter 3 and there is no need to repeat those discussions

here. I suspect that these demographics are influenced at least in part by the fact that the majority of participants came from a database of people who have indicated to the Institute of Psychiatry in the past that they are happy to be contacted about engaging in research. Many of them may be university students or staff and by actively volunteering to take part and potentially having been engaged in past research projects they may be a slightly biased sample population.

As discussed in chapter 1, minimal work has been done to assess the effectiveness of tick protective intervention materials at a follow-up period. This pilot RCT tried to investigate the impact of intervention materials on the performance of tick checking behaviour at a follow up period of approximately 6 weeks. It was hoped that during this follow-up period participants would have an opportunity to engage in outdoor activities in some of the areas where ticks are known to be present. Given the time constraints of a PhD, 6 weeks was the longest follow-up period that could be allowed. Importantly, two bank holiday weekends fell within the follow-up period increasing the number of opportunities available for participants to engage in outdoor activities. By choosing this time period I hoped that participants would be more likely to engage in outdoor activities and also to be at greater risk for coming into contact with ticks, therefore making the intervention materials of greater relevance to them. I would recommend that a full-scale RCT runs for a longer follow-up period during the spring or summer in order to account for these issues.

The existing tick information and the resulting control intervention listed a variety of behaviours that could be adopted to prevent tick bites and tick-borne disease. They also mentioned the performance of tick checking behaviour, but there was no explanation about what this meant or how one is correctly carried out. Instead, the focus seemed to be on behaviours such as using tick repellent or wearing long trousers. On the other hand, the two experimental interventions placed the focus on performing a tick check rather than any of the other behaviours. The reason for this was that tick checking behaviour was the main outcome measure for this study and was also the most complex of the recommended preventive behaviours. People know how to perform behaviours like wearing trousers and applying a repellent and they engage in them regularly for reasons unrelated to ticks or tick-borne disease. However, asking someone to 'perform a tick check' is something that is open to interpretation as evidenced by the number of questions and comments about it garnered in both the public interviews and the survey. Because of this it seemed more appropriate to

target only tick checking behaviour in this study, particularly given that it is only a pilot randomised controlled trial. Perhaps a future, larger scale trial might look at the range of preventive behaviours.

The current study collected information about the average time spent reading the intervention material, with an overall average of 3 minutes 30 seconds. Based on the amount of information and the time it took participants to read it during the read aloud pilot testing this seems like a short amount of time. Some participants may have taken the time to thoroughly read through the information, but others are likely to have done a much more superficial read through. Although this may be the case, I adopted the intention-to-treat approach (Polit & Gillespie, 2010). This meant that I analysed all participant data as if they had read the leaflet fully, regardless of whether they had actually adhered to the instructions to do so or not. When looking at the average reading time by intervention group, it appears that participants in the control group spent an average of 5 minutes reading the materials. This is longer than either the conventional health psychology based or disgust reduction groups who spent an average of 3 minutes 10 seconds and 2 minutes 20 seconds respectively. The control intervention text was slightly shorter than the two experimental interventions (792 words, 840 words, 946 words respectively) so perhaps participants found this to be a less daunting amount of information and were therefore more likely to spend time reading it properly. Alternatively, it may be the case that the information contained in the control leaflet was less clear, requiring more participants to return to the information and to spend a longer amount of time reading it. It is important to note that average time spent reading each leaflet is based only on the first visit to the leaflet page and does not take into account the time spent re-visiting the page. It would be useful for a future study to capture the time spent on any return visits to the information leaflets as this could reveal further differences between the study conditions.

Implications for communication

A finding of particular importance regarding the communication of tick and tick-borne disease messaging to the public was that the provision of such information resulted in almost no reports of avoiding the countryside. This was in line with findings of a study by Marcu, Barnett, Uzzell, Vasileiou, & O'Connell, (2013) which showed that having experience of Lyme disease was not associated with any withdrawal from the countryside. This was an encouraging finding as it indicates that the public are receptive to the provision of appropriate and effective

messaging and are unlikely to view it as scaremongering or anxiety producing (Hallman et al., 1995).

The results indicated that there was a lowering of behavioural intentions and engagement with regards to tick checking during the follow-up period between T2 and T3. Based on a previous study by Lawless et al., (1997), this was not an unexpected finding, but the reasons behind this drop in behaviour and intentions may be of interest and need to be carefully considered and addressed when developing communication materials. Among participants who reported at follow-up that they had been walking but not engaged in tick checking behaviour the most common reasons for this were forgetfulness and the belief that checking for ticks was not really necessary. These same reasons were also reported by participants who had not been walking during the follow-up period but who said that they did not intend to check for ticks in the future. 'Forgetfulness' suggests that participants who had been walking but did not check had intended to do so and that if they had remembered about the behaviour they would have practiced it. Among those who had not been walking, 'forgetfulness' seems to have remained as a potential barrier that some participants felt would affect their ability to engage in tick checking behaviour in the future and perhaps requires further investigation. Alternatively, those participants who reported that they did not believe that tick checking was necessary, regardless of whether they had been walking or not, are perhaps people who will never change their views about the importance of tick checking behaviour. Recent research into the uptake of the seasonal influenza vaccination revealed that not all patients wished to be notified about the availability and importance of vaccination, with the study authors suggesting that some people had already made up their mind about vaccination and were perhaps in less need of notification (Van Rossem, Vandevoorde, Buyl, Deridder, & Devroey, 2012). A similar situation may have been identified in this study, where participants may already have made an assessment about their likelihood of being bitten by a tick and developing a tick-borne disease. This could be a result of having spent time in the listed locations and not having experienced any contact with ticks, therefore reducing the perceived relevance of any behaviour change messaging. However, if this is the case then it could be argued that these people actually require more information and guidance to help them inform their choices. Based on the results of this pilot RCT, it seems that the inclusion and application of elements from theories of health psychology were particularly effective at encouraging behaviour change. As a result, these should be considered when designing communication materials for use with the public.

CHAPTER 6: DISCUSSION AND CONCLUSIONS

Summary of Findings

Tick-borne disease in the UK continues to increase (Public Health England [PHE], 2012). Despite this, little research has been done in the UK to identify effective interventions, to understand current levels of knowledge and perceptions toward ticks and tick-borne disease, to identify barriers to or drivers of different tick protective behaviours, or to design and test different intervention materials aimed at increasing these behaviours. Each of these gaps was addressed using separate strands of research.

I had six aims at the start of this thesis (see chapter 1):

Aim 1 (Literature review): Identify interventions that effectively increase protective behaviour

Interventions that could increase tick protective behaviour were identified through a systematic literature review as detailed in chapter 1. This review revealed that there had been a relatively limited amount of research done to evaluate communication materials about ticks or tick-borne disease. Three randomised controlled trials have been done to assess intervention materials; however the majority of existing studies were observational in nature. From these few studies there was some suggestion that educational interventions aimed at increasing the uptake of tick protective behaviours could be effective (Lawless et al., 1997; Malouin et al., 2003; Daltroy et al., 2007). Existing studies have tended not to focus on changing behaviour, but instead on increasing knowledge and understanding of perceptions towards ticks and tick-borne disease. A range of factors were identified as predictors of engagement in tick protective behaviours. These included perceived likelihood of being bitten by a tick or of developing a tick-borne disease (Beaujean et al., 2013; Brown et al., 1992; Herrington et al., 1997; Herrington, 2004), perceived severity (Beaujean et al., 2013; Daltroy et al., 2007), past experience (Brown et al., 1992; Herrington et al., 1997; McKenna et al., 2004), knowledge (Beaujean et al., 2013; Brown et al., 1992; Herrington et al., 1997) and perceived efficacy of the recommended behaviour (Beaujean et al., 2013; Daltroy et al., 2007; de Vries and van Dillen, 2002).

By carrying out a systematic review I was able to identify deficits in the existing research literature which I could target with my research. These included explicitly using psychological

theory to guide intervention design, looking at tick checking behaviour over a reasonable follow-up period to see if it is maintained, developing an RCT to determine the effect of different intervention materials and analysing each predictor variable individually to see if it influences tick checking behaviour. This systematic review has since been published in a peer-reviewed academic journal (Mowbray, Amlôt, & Rubin, 2012).

Aim 2 (Expert interviews): Identify knowledge and perceptions of tick-borne disease in the UK

The evidence from the existing literature provided guidance for designing and undertaking data collection through the form of qualitative interviews (chapter 2). Initial interviews conducted with UK-based topic experts provided details of recommended and effective tick protective behaviours which included wearing light coloured trousers, tucking trousers into socks, sticking to clear pathways, the use of a repellent and the performance of tick checking behaviour. Topic experts also suggested that they felt that knowledge might be low among the general public and were concerned that an attempt to increase awareness of ticks and tick-borne disease might result in people avoiding the countryside.

Aim 3 (Public interviews): Identify drivers of and barriers to tick protective behaviour

Interviews with the general public (chapter 2) provided insight into the factors that influence the uptake of protective behaviours. Overall, knowledge about ticks, tick-borne disease and the importance of protection was low, with personal experiences playing a key role in determining levels of knowledge. Risk perceptions appeared to be important in determining whether or not someone engaged in a protective behaviour. Participants generally reported low levels of perceived likelihood of being bitten by a tick or developing a tick-borne disease, and were therefore unlikely to see the necessity of taking protective actions. The same held true for perceptions of disease severity. Numerous barriers to the uptake of primary protective behaviours were identified including social norms, health concerns, time commitments, hassle, forgetfulness and a lack of awareness. Barriers that were identified as being specific to the secondary prevention behaviour of tick checking were forgetfulness, the amount of time involved and not knowing what a tick check is or why it is important. Behavioural barriers also existed with regards to tick removal. These included a lack of knowledge about the removal process, confusion about removal, low levels of removal confidence and feelings of disgust towards removal. Contrary to concerns from topic experts, participants all said that knowing more about ticks or tick-borne disease would not act as a barrier to them engaging in outdoor activities. These details can all be found in the topic

expert mental model and the public mental that were included in chapter 2 (expert interview results and public interview results sections respectively).

Aim 4 (Web survey): Determine which factors are most strongly associated with the uptake of protective behaviours

The drivers and barriers to the uptake of tick protective behaviours that were identified during interviews with the public were tested for associations with tick checking behaviour using a quantitative web survey, described in chapter 3. The results showed that those who reported lower levels of disgust towards ticks were more likely to report engaging in tick checking behaviour (chapter 3, table 3.4). Tick checking behaviour was also associated with higher levels of tick removal confidence (efficacy), greater perceived likelihood of tick bites, greater general knowledge, greater perceived control and greater perceived severity (chapter 3, table 3.4). Those who reported finding a tick check time consuming or something that they would forget to do were less likely to report having engaged in any tick checking behaviour (chapter 3, table 3.4).

The web survey also confirmed findings from the public interviews which suggested that the majority of participants had low levels of knowledge about ticks and tick-borne disease, often being unable to correctly identify a tick or effective removal strategies (chapter 3, figures 3.9 and 3.10). Most participants had never checked for ticks reporting that the reasons for this were because they would forget, they did not believe that a check was necessary and they did not know how to perform a check (chapter 3, figure 3.6).

An article covering the qualitative interviews and the quantitative web survey has been submitted to a peer-reviewed academic journal.

Aim 5 (Pilot RCT): Design and preliminary test of the effectiveness of communication materials at increasing the uptake of protective behaviours

As detailed in chapter 4, three communication interventions were created based on existing materials and the results from the qualitative and quantitative studies. Read aloud pilot testing with members of the public helped to refine the messaging to ensure that the two experimental interventions contained elements of health psychology theory, and that participants responded positively to those messages. The read aloud process was also useful

for trialling the disgust reduction messaging and gaining participant feedback about whether this messaging was appropriate and effective.

Having completed the read aloud process, the pilot RCT determined that there was no statistically significant difference in tick checking behaviour across the intervention groups at baseline or immediately following the provision of the intervention. At the time of the 6 week follow-up questionnaire, participants in the health psychology based group who had been to a tick affected area were significantly more likely to report having engaged in tick checking behaviour compared to those in the control and disgust reduction groups. There was no significant difference in behavioural intentions among those who had not been to a tick affected area at follow-up. There were also no significant differences in the uptake of the secondary outcome behaviours across study time points as a result of intervention group. However, some caution is needed because of low sample size.

Aim 6 (Pilot RCT): Determine the sample size for a full RCT

Data from the pilot RCT (chapter 5) was used to determine that the necessary sample size for a full-scale RCT would be 32 participants in each arm of the study who had been walking during a follow-up period. Taking into account the drop-out rates at each stage of the study, this would require a minimum of 1786 people to be initially contacted about taking part. An online survey programme was deemed to be a suitable for running the online trial as randomisation worked effectively and there were no reported problems with the programme.

Implications

Implications for future research

The pilot RCT identified a number of implications to be considered when undertaking future research in this field. Most obviously, as intended the research provided useful suggestions to improve the design of a future RCT testing interventions to increase performance of tick checking behaviour. First, knowing the sample size needed for a full-scale RCT is of use to future research as this is needed for the design of an effective study. This is not simply a matter of calculating the number needed for the final analysis. Knowing the proportions of participants who are likely to meet the inclusion criteria, volunteer to take part, complete all aspects of the study, and have spent time walking in a tick exposed area has allowed me to determine the minimum number who should be approached if the study is to have sufficient statistical power.

Second, this trial allowed for testing the delivery of an intervention-based RCT via an online survey. Initially the online survey programme was not able to randomise participants to intervention conditions, but with the help of an IT specialist, the program was able to do this successfully and all participants were able to access and complete the trial without problems. This indicates that using an online web survey program is a viable way to run such a trial, assuming that it has a suitable mechanism for randomisation. Delivering the intervention and collecting data online had the added benefits of reducing costs for the research team and time commitments for the participants. Conventional RCTs have been criticised for being expensive to run (World Health Organisation [WHO], 1998), but because all participant contact was carried out online there were no costs associated with distributing the intervention materials or questionnaires. In addition, all data was collated by the survey program. As a result, data processing was less time consuming, with some preliminary descriptive analysis conducted by the survey program itself. It is worth noting that this method is useful in a population where the majority of participants have access to the internet, but this may not be appropriate in other situations. Future research should also address the issue of participants being able to return back to look at the leaflet.

Several broader implications for researchers also arose from this work.

First, the study provides a model for the testing of future tick intervention materials aimed at other populations. This research has focused on a population who live in an urban environment, but who are at risk of tick bites through engagement in outdoor activities. This population is under researched in the tick-borne disease literature. Their irregular contact with the risk and reduced knowledge makes them of particular interest. However, this is not the only population who could come into contact with ticks and it would be beneficial if future research looked at a variety of other population groups such as children, people who live in at risk or newly at risk areas and people who are occupationally at risk of tick bites. Some research has been done with these populations (de Vries & van Dillen, 2002; Gould et al., 2008; Nolan & Mauer, 2006), but to the best of my knowledge, none of it has been specifically focused on testing intervention materials with these populations in the UK.

Second, this research has shown that theories of health psychology can be used to effectively increase the uptake of tick protective behaviours, particularly the performance of a tick check,

which was my key outcome measure. A future, full-scale trial should incorporate these theories and aim to further investigate the impact that different variables have on tick protective behaviours. For instance, self-efficacy, or respondents' confidence in their ability to perform a tick check, was found to be an important predictor of tick checking behaviour in this study. This has been repeatedly found in the literature on predictors of other forms of health-protective behaviour (Strecher, McEvoy DeVellis, Becker, & Rosenstock, 1986), but a full-scale RCT would be able to provide more detailed information about the strength of this relationship, particularly within different populations. More generally, this research has shown the benefit and importance of incorporating theories of behaviour change and health psychology into public health information. Regardless of the health topic there is both scope and precedent for including aspects of these theories in the design of communication materials (Michie & Abraham, 2004).

Third, the pilot study has shown that it can be useful to separately identify and assess the predictors of each individual protective behaviour. Previous studies have tended to look at the predictors of all tick protective behaviours taken in combination (e.g. Brown et al., 1992; Hallman et al., 1995; Herrington, 2004). This type of analysis is not ideal as there are likely to be differences in the psychological predictors of different protective behaviours. In fact, my research has indicated that these differences do exist. For example, self-efficacy was found to be a strong predictor of tick-checking behaviour, but was not significantly associated with other tick protective behaviours such as sticking to clear pathways or using a repellent. Knowing the predictors of particular behaviours is an integral part of being able to target communication messages appropriately and effectively. This approach could be of use for research into behaviour change in any domain.

Finally, there is scope for future research to examine the role of disgust with regards to behaviour change. The pilot RCT found that messaging aimed at reducing levels of disgust about ticks and tick-borne disease among members of the UK public appeared to have an unhelpful effect. While the messaging was meant to provide reassurance and encourage the uptake of tick checking behaviour, it appeared that the intervention reduced the likelihood of behaviour change in comparison to an intervention based solely on conventional models of health psychology. Further research needs to be done to investigate the relationship between disgust and behaviour change as it does not seem to be as straightforward as previously thought. In addition, it would be beneficial for future research to assess the net effect of

using disgust messaging to encourage tick checking behaviour. While higher levels of disgust may reduce willingness to engage in tick checking, an advertisement campaign that uses disgust messaging may reach more people and be attention grabbing. If this was the case, it would be useful to know whether the overall effect of reaching so many people with a message resulted in an increase in checking behaviour at the population level, or whether the disgust element would outweigh any behavioural engagement.

Links for theory

Use of health psychology and behaviour change theories

Theories of health psychology and behaviour change played a crucial role in informing and driving the intervention materials used in this study. Many of the main components of theories such as the theory of planned behaviour and the health belief model were important in determining the content and delivery of the experimental interventions. For example, the role of self-efficacy in behaviour change was evident from both the public interviews where participants discussed their concerns about their ability to safely remove ticks and from the survey where these findings were again echoed in the data. Having identified self-efficacy as a behavioural driver it was addressed in the experimental leaflets by providing participants with greater detail and reassurance regarding the tick removal process. Risk perceptions are also central to theories such as the health belief model and protection motivation theory and their importance with regards to the uptake of tick protective behaviours was obvious from the interview and survey data (Abraham & Sheeran, 2005; Norman et al., 2005). Participants wanted to have information about topics such as disease severity and likelihood in order to help them make more informed risk assessments which in turn could affect their behaviour. The leaflet interventions attempted to address current risk perceptions by providing more detailed information on tick risks. Theories such as social cognitive theory and the health belief model also explain the importance of benefits and barriers to behaviours (Luszczynska & Schwarzer, 2005; Abraham & Sheeran, 2005). A number of barriers were identified during interviews and then quantified by the survey in terms of their prevalence. In an attempt to increase the uptake of tick protective behaviours these barriers were addressed in the experimental leaflets and solutions to minimise or remove the barriers were suggested.

The elements of health psychology that my research identified as predictors of tick protective behaviours are largely similar to those found by existing research. Both response and self efficacy have been shown to impact the uptake of tick protective behaviours (Beaujean et al.,

2013; Daltroy et al., 2007; de Vries & van Dillen, 2002) as has increased knowledge of ticks and tick-borne disease (Beaujean et al., 2013; Brown et al., 1992; Herrington et al., 1997), and greater perceived likelihood of coming into contact with a tick or being bitten by a tick and developing Lyme disease (Beaujean et al., 2013; Brown et al., 1992; Herrington et al., 1997; Herrington, 2004). Each of these variables were also found to be predictors of tick protective behaviour (particularly the performance of a tick check) by my web survey as detailed in chapter 3. Existing research also indicates that perceived severity of tick bites and tick-borne disease can predict engagement in tick protective behaviour (Beaujean et al., 2013; Daltroy et al., 2007), although this finding is not uniform across studies with other research suggesting that severity is not significantly associated with such behaviours (Hallman et al., 1995; Heller et al., 2010). My research highlights this unclear relationship between perceived severity and engagement in tick protective behaviours. I found that viewing Lyme disease as a serious condition was significantly associated with the uptake of tick checking behaviour, but there was no significant association with wearing trousers when walking, tucking trousers into socks, sticking to clear pathways, or the use of repellent. Research by Daltroy et al., (2007) used elements of health psychology theory to develop the tick protective intervention materials that they tested in an RCT with members of the US public. They saw an increase in tick protective behaviours among participants in the experimental intervention group, just as my research did with the health psychology based intervention.

Use of mental models

The mental model that was developed based on interviews with members of the public played a large role in shaping the two experimental interventions. Each of the recommended protective behaviours from wearing long trousers through to the tick removal process and keeping an eye on the bite site were mentioned in the interventions. Many of the barriers to these behaviours such as social norms and forgetfulness were also dealt with in more detail as were some behavioural drivers. Both participant risk perceptions and knowledge and awareness were influential aspects in determining what information was included in each of the interventions. Less obvious was the inclusion or influence of the experience aspect of the mental model. At both the primary and secondary prevention stages of the model the root behaviour driver in this study was experience. Both social and personal experiences were discussed in participant interviews and these in turn influenced knowledge and perceptions. Therefore, although the intervention process did not obviously state the influence of

participant experiences on their design, these experiences were included indirectly through their influence over reported knowledge, perceptions and behavioural barriers.

The mental model approach was useful for developing targeted health communication materials. Qualitative data can often be difficult to synthesize and represent in a non-textual format. Often it can be easier to explain data in a visual way as the key findings do not get lost in a paragraph of text. Mental models are effective at representing the key themes within health data. They are able to show all of the items that influence a behaviour, as well as the direction of influence. Although these models may sometimes appear chaotic, this is actually an excellent representation of the complexity of a particular behaviour. In addition to finding the mental model approach to be an ideal strategy for organising my qualitative data, I also found them to be accurate predictor models of my quantitative research outcomes. For instance, the public mental model highlighted that risk perceptions about disease likelihood and severity were drivers of tick checking behaviour and this was confirmed through the quantitative data analysis. Although the survey data was still necessary in order to quantify behaviours and assess the strength of associations, the mental models made it easy to know which variables to investigate.

Disgust

An intriguing finding from this PhD was the role of disgust. One of the ways in which the disgust version of the intervention differed from the other versions is that it attempts to use more technical language about ticks in order to try and reduce or alleviate some of the feelings of disgust that some people experience in relation to this topic. During the interviews participants who reported feeling some disgust towards ticks explained that it was associated with the fact that ticks burrow into the skin and feed on blood. Disgust was also elicited by the way that ticks increase in size while feeding. By reducing references to 'blood sucking' and 'burrowing' it was hoped that a reduction in disgust would follow. Research suggests that disgust may play a key role in the development and maintenance of phobias such as blood-injection-injury phobia (Sawchuk, Lohr, Tolin, Lee, & Kleinknecht, 2000). Data has shown that exposure to blood-injury stimuli can cause emotions of aversion and nausea among blood-injection-injury phobics, (Gross & Levenson, 1993) both of which are also elicited when experiencing disgust. Furthermore, disgust has been shown to result in a lowered blood pressure and heart rate (Kelly, 2011) and after a brief initial increase, this is also evident in blood-injection-injury phobia patients indicating a relationship with the emotion of disgust (de

Jong & Merckelbach, 1998). Results of a study by Sawchuk et al., (2000) confirm previous research which found that higher levels of disgust were associated with higher scores of blood-injection-injury phobia measures. Although it is unlikely that interview participants for this study had any blood-injection-injury phobias, it is not surprising that participants who reported feeling an emotion of disgust towards ticks and tick bites linked this disgust to the blood-related aspects of ticks. Research into blood phobias can also help to explain the survey findings which indicated that higher reported levels of disgust towards ticks actually resulted in decreased performance of tick checking behaviour. Rosin, Haidt and McCauley (1993) divided disgust elicitors into two separate categories, one of which is termed animal-reminder disgust. This type of disgust is associated with emotional revulsions to stimuli that act as reminders of the 'animalness' of humans (Sawchuk et al. 2000). These stimuli include things such as blood and veins because of their similarity to the physical properties of humans, thus eliciting a strong animal-reminder. This animal-reminder disgust sensitivity results in disgust-motivated avoidance, whereby eliciting disgust can cause someone to engage in avoidant behaviour in order to minimise perceived risk of infection or contamination (Sawchuk et al. 2000). These findings fit with and lend further credibility to the theory of experiential avoidance as discussed in chapter 3, which posits that individuals attempt to avoid unpleasant emotions even if this has more severe consequences in the longer term (Hayes et al., 1996). To counteract this avoidance, the disgust intervention focused on informing people that dealing with a tick-borne disease would be much worse and much more disgusting than taking a moment to find and remove a tick.

It is interesting that in different contexts, disgust can act as either a driver of or barrier to health behaviours. My research findings seem to side with the theory of experiential avoidance, with participants who are disgusted by ticks and tick-borne disease appearing to be less likely to engage in a tick check to avoid these unpleasant emotions. Research into other health behaviours such as hand-washing shows an opposite effect which is more in line with the theory of the behavioural immune system (Curtis, de Barra, & Aunger, 2011; Judah et al., 2009). Perhaps these differences indicate that the effects of disgust are not uniform, and that they change based on both the elicitor of disgust as well as the behaviour being targeted. For instance, disgust towards ticks appears to be in relation to ticks feeding on one's blood, rather than on their ability to transmit disease. Alternatively, hand-washing is a response to the disgust associated with bodily waste and other contaminants that are perceived with disgust by all humans due to their ability to make us ill (Curtis et al., 2011). Although tick-borne

disease is largely viewed as unpleasant and undesirable, the process of becoming ill due to a tick bite does not seem to provoke the emotion of disgust. It may be this difference that determines whether disgust causes us to avoid or engage in a behaviour.

Given that encouraging the public to engage in some health behaviours requires a reduction of disgust reactions there is a need for greater understanding about how this can be done most effectively. The majority of the literature addressing disgust reduction does so with regards to a clinical setting rather than as part of a health messaging campaign. There seems to be a gap in knowledge about how to tackle disgust with a particular need to determine how disgust actually works in practice. There may be a nuanced association between disgust and the uptake of health behaviours with aspects such as the strength of disgust, the particular behaviour being targeted and the other messaging that has been incorporated all playing important roles. The timing of messages may also be crucial to disgust as a driver of behaviour change. For example, Judah et al., (2009) found that disgust was a powerful predictor of hand-washing behaviour in motorway restrooms. However, these messages were provided directly at the time when the behaviour would take place providing a cue to action and took place in a context where other behavioural barriers such as lack of hand-washing facilities or time were not present. Alternatively, my study provided messaging in isolation of when and where the intended behaviour would take place and as a result, potentially reducing the salience of the messaging.

Implications for practice and policy

During the final year of my PhD I have been involved in the evaluation and update of the existing tick information materials designed by Public Health England (PHE) colleagues who were on the steering group of this PhD research. This process involved the design of new communication materials for use on the PHE website as well as distribution to members of the public. In collaboration with PHE colleagues I provided input into messaging about tick protection strategies, based upon the findings of the research detailed in this thesis. My contribution was specifically to ensure that information about protection strategies focused on encouraging the performance of tick checking behaviour. This was done by addressing the barriers to this behaviour as identified through this research. A leaflet and a poster were developed from these collaborations and were publicized by PHE through tweets on the social media site, Twitter, and through a BBC news story on May 12th 2013

(<http://www.bbc.co.uk/news/health-22468181>). This news story increased publicity for the

topic and provided a link to the communication materials as found on the PHE website. These materials can be seen in appendix 25. I have received feedback from senior members of staff at PHE expressing their support and thanks for my contribution and this can be found in appendix 26. My research has helped to ensure that appropriate and tested messages are available for use in areas where ticks are currently endemic and will be ready for rapid distribution in areas where ticks may become endemic in the future. This research has provided a set of tested messages for use in tick endemic regions across the UK allowing everyone to access the same risk communication messages and interventions. The knowledge and materials developed during this research have directly informed the work of Public Health England in this area; thereby translating the research into public health promotion and protection practice.

A clear implication for practice and policy makers that has become evident throughout this research is that public health messaging cannot be developed solely by topic experts. Although experts certainly have an important role to play in message development and review, it is necessary to involve the public or the target audience in this process. The qualitative interviews that I conducted with topic expert and members of the public highlighted the importance of target audience input. Much more detail emerged about behavioural predictors during the public interviews that it did from the experts. Furthermore, information from the two groups did not always match as in a number of instances topic experts had failed to mention predictors that had been discussed by the public. It is encouraging that the development of risk communication materials regarding tick-borne disease in the UK will now be based on both expert and target audience input.

My research also has implications for how organisations such as PHE develop and test public health communication materials. It has provided an example for involving members of the public or target audience in the message design, and also for testing communication materials before their deployment. The importance of testing was made clear from the unexpected results of the pilot RCT. Although the disgust reduction intervention was designed based on interview and survey data, this data did not provide any suggestion that the disgust reduction intervention could actually reduce desired tick protective behaviours. Only by pilot testing the interventions with the target audience did this unexpected result become evident. There are plenty of examples of public health programmes that have produced unintended and negative results among populations (Rosen, Manor, Engelhard, & Zucker, 2006). These cover a range of

health behaviours in a variety of locations including smoking and alcohol use among Australian adolescents (Hawthorne, Garrard, & Dunt, 1995) and the HIV and needle exchange programmes in Vancouver (Strathdee et al., 1997). Given that these kinds of unexpected results are not uncommon in public health campaigns it is beneficial to engage in intervention testing. While my research has been focused on communicating about ticks and tick-borne disease, the process that I have gone through to develop and test these materials is applicable to any health behaviour and can therefore serve as an example of how PHE may develop future messages.

Beyond PHE, my research also has implications for other groups tasked with communicating the risks from ticks and tick-borne disease to the public and professional groups as well as various other outdoor locations and groups. Although I developed and tested my intervention messages with a population who live in an urban location and are at risk of tick bites through engagement in outdoor activities, some of the messaging techniques are likely to be relevant to the general public. The PHE leaflet has already been made available to members of the public via a download from the website and has also been disseminated to groups such as UK veterinary practices. While further message tailoring and refinement may be necessary for different populations, this leaflet provides a good starting place and fills the gap for a nationally informative and applicable intervention.

Strengths and Limitations

My research had a number of strengths. Although the overall project was made up of several smaller studies, each of these fitted together in a progression towards one joined up piece of work. Beginning with a systematic literature review allowed me to assess the existing state of play in this topic area while also highlighting gaps in the research that I could ultimately address. Discussion guides for the interviews with both topic experts and members of the public were designed based on findings from the literature review. These interviews themselves then began to provide a picture of some of the issues surrounding ticks and tick-borne disease in the UK as well as the drivers of and barriers to the accepted protective behaviours. To build on this qualitative data and be able to assess the strength of each of the predictor variables I designed and ran a quantitative web survey. This gave me an understanding of which variables were most likely to influence tick checking behaviour and these were then incorporated into the design of the experimental intervention materials.

Few previous studies appear to have tested intervention materials during the tick season which, in the UK, typically runs between April and September, although this is weather dependent. By running a trial during this period I hoped that participants would be more likely to engage in outdoor activities and therefore have more opportunities to practice tick protective behaviours. Although some participants did go to tick affected locations during the study follow-up period between T2 and T3, it would have been preferable to have had a follow-up period that was longer than approximately 6 weeks.

Some measurement issues were evident in this research. First, by relying on self-report data there is the chance that some participants may have reported that they engaged in tick checking behaviour when in fact they did not. Having read the intervention materials it would have been obvious to participants that I was looking for them to engage in the recommended behaviours when in one of the listed locations. Participant responses may therefore have been guided by the social desirability bias if they felt that they were expected to report engaging in the behaviour. Also, there is still a need for future research to focus on gaining direct measures of behavioural engagement rather than relying on self-report data. Within this study I was able to capture some behavioural data, but this was still reliant on participants reporting whether or not they had engaged in the behaviour. Although it can be difficult to collect data from a direct measure of behaviour the results would be of greater accuracy and reliability. Even in this pilot study where the behaviour was self-reported, I found that among those participants who had been walking during the follow-up period, a total of 63% reported that they had engaged in tick checking behaviour. Among participants who had not been walking the intention to engage in tick checking behaviour the next time they went walking was 84%. These numbers highlight the difference that exists between intention and behaviour and why it is so important to gain direct behavioural data.

Second, readers should be aware of the limits to the generalisability of this study. As discussed in chapters 3 and 5, the data is specific to members of the public who live in an urban area and visit tick affected areas for recreational activities. This was a strength in some ways as this group were likely to be at risk given that knowledge was low due to living in an urban area, but risk was high because they visited tick affected areas. Also, as far as I am aware, no previous research has focused on this population group. However, the data that may not be generalisable to other at-risk populations. The majority of participants who engaged in my

research were White, well-educated and fairly affluent. A full-scale study should aim to represent greater demographic diversity.

Critical Reflection

Any future work around the development of information-based interventions for tick-borne disease within the UK should consider a number of factors. First, the work here has shown that theories from the field of health psychology can be applied effectively to increase the uptake of tick protective behaviours among the UK public. It would perhaps be useful if future work built on this finding by investigating if particular theories are of greater relevance to tick-borne disease than others or whether applying aspects drawn from several theories is the most beneficial approach. Modern developments in behaviour change research have tended towards the integration of multiple theories as a pragmatic way for policy makers to consider the options that are open to them (Michie, van Stralen, & West, 2011). Using the insights that are being derived from this approach may help us to develop novel or improved behaviour change techniques in the specific field of tick protective behaviours.

Second, this research has raised many questions about the role of disgust with regard to tick-borne disease. It proved difficult to decrease levels of disgust through an information leaflet and I believe this highlights the need for future research to address questions about how disgust can impact upon tick-protective behaviour and whether it can be used as part of an effective strategy for increasing the uptake of protective behaviour. Additionally, it was perhaps overambitious to expect that a simple leaflet intervention could have a major impact on the emotion of disgust; however a leaflet may be one of the only forms of intervention that PHE can realistically implement. This reflects a tension that exists between the scientific researcher who is interested in whether, in theory, disgust is important to behaviour change, and the public health practitioner who is interested in whether, in practice, disgust has any role to play in a public health intervention. Future researchers need to be clear about which of these, theory or practice, is the focus of their study.

Third, with any study it is important that the study sample is representative of the entire population in whom we are interested. In this case, it was the entire population of urban dwellers who place themselves at risk in a rural environment, but future researchers may be interested in a wider population, or only in people who live in affected regions. Ensuring a representative sample is difficult. It is possible to take steps to ensure that samples are demographically representative, but it is important to note that the sample in this study may not have been, given that the majority were well-educated and white. Even if a study is

demographically representative, this does not guarantee that it is psychologically representative. In an era of low response rates to surveys, we may need to be more imaginative in how we test our interventions. A future study, for example, may choose to use block randomisation of entire locations to receive an intervention, with observational methods then being used to identify any impact on observable behaviours within the population as a whole.

Fourth, the starting point for intervention design was existing leaflets on the topic of tick-borne disease prevention. Although much of the content and wording of the two experimental versions of the leaflet was developed based on the results of the qualitative interviews and quantitative web-survey, it was also influenced by the existing materials. Future research could develop intervention materials from scratch to help mitigate this influence and could perhaps also investigate the impact of different presentation styles which was not within the scope of the current research.

Finally, this research did not make full use of all the data that could have been collected. For example, demographic data were not collected for participants who started, but were ineligible to take part in the study. This data could have been useful for the design of any future research as it could help to answer questions about who is most likely to take part in and complete the study. It is also possible that participants who completed the web-survey may also have completed the pilot RCT, but the relevant data were not collected and there was no mechanism in place to render previous participants ineligible. These are important issues for any future research to take into consideration in order to strengthen the validity of the results. Also, alternative approaches, such as inputting missing values for each participant based on their other responses may have provided a larger sample size for the final analysis. Different analyses were also possible with the data. For example, an argument could be made for using regression models to test the impact of the interventions within the RCT, using baseline scores as covariates to control for any pre-intervention differences in the propensity to check for ticks, and comparing both experimental interventions to the control condition simultaneously for each outcome variable. Additional planning for the analysis of a future RCT, using the current data as a guide, will be worthwhile.

Key Recommendations

There are a number of recommendations that have come out of this research.

First, theories of health psychology need to be considered when designing public health communication materials or interventions. My research showed that aspects of these conventional theories including the use of behaviour change techniques were particularly effective at increasing tick checking behaviour.

Second, as has been found by previous research, knowledge appears to be an important predictor of engagement in tick protective behaviour. Given this, it may be tempting to suggest that simply providing people with information about ticks and recommended protective behaviours may be enough to induce behaviour change. However, knowledge is not the only predictor of behavioural uptake so it is important to ensure that other predictors such as self-efficacy are also addressed to make intervention materials as effective as possible.

Third, the impact of disgust on the uptake of health behaviours needs further investigation. The relationship between disgust and particular health behaviours appears to be nuanced, so caution needs to be taken before it is employed. Future research should investigate the direction of this impact before incorporating disgust into any public health behaviour change campaigns.

Fourth, public health materials should not be designed solely on the input of topic experts. Experts must be involved in the process to check facts and provide feedback and guidance, but my research has shown that there are marked differences between how experts anticipate the public will behave and how the public report behaving. Using mental models to organise and represent the data made these differences particularly clear.

Fifth, an online survey programme is a viable and cost-effective way to conduct an RCT. Randomisation of participants to intervention groups worked effectively and built in data processing tools made summarising and analysing the resulting data quicker and easier.

Finally, given that PhD research will always be completed with limited time and resources it is important to be able to pin point which aspects of a study such as this one are necessary to obtain results and which, if any, could be bypassed in a future study. It is difficult to make this

decision as the literature review, qualitative interviews, quantitative web survey and pilot RCT each added new data that was used to inform and direct the subsequent research. My recommendation for future research aiming to develop public health communication materials would be that the ideal study design would begin with a review of the literature followed by mixed methods data collection and a pilot RCT, however if time and resources are scarce then the process could be streamlined. It is absolutely necessary to conduct a systematic literature review before undertaking original research. It comprises a full picture of what research has already been done and provides evidence for the need and importance of new research. An aspect of the methodology that could be simplified is the use of qualitative interviews. Input from topic experts enhanced and focused my research, but there may be other less time-consuming ways to collect this data. For instance, some of the expert data could be found during the literature review, or rather than running individual interviews, engagement with a stakeholder group may be a way to gather this data. Although this method of obtaining data from topic experts would not be as systematic or detailed, it is likely to garner similar results in a much shorter period of time. Interviews with members of the public provided me with useful data about which behaviours to target as well as what variables could be predictors of those behaviours, but I do think it may be possible to skip this step. While I used the interview data to develop the web survey, I think this could largely be done based on the theories of health psychology that were guiding my research. The resulting survey would perhaps be longer and not as focused on particular predictor variables, but the findings would remain similar. I do believe that the survey was a crucial part of the research as it revealed results, particularly regarding disgust, that were not evident through the qualitative data. With regards to the testing of intervention materials, there may be some temptation to forgo a pilot RCT and instead immediately run a full-scale study. Although this might cut down the amount of time that needs to be invested in the research, a pilot RCT has real benefits both in terms of overall cost-savings as well as increased efficacy of the intervention (Feeley et al., 2009).

Conclusions

My research as a whole has shown the importance of engaging both topic experts and members of the public in intervention design, identifying and understanding the relationships between predictors and protective behaviours and the need to test and refine interventions prior to rolling them out for use with the public. Furthermore, I have added to existing research by targeting an at-risk population that has not previously been studied in the UK and by investigating the use of disgust as a driver for increasing tick protective behaviours. Based

on this research, the success of interventions aimed at increasing tick protective behaviours is dependent upon using aspects of recognized health psychology theories to deliver information. Ultimately, there is a need to increase UK public awareness about ticks and tick-borne disease risk as well as to encourage the uptake of protective behaviours. By designing communication materials based on research involving the target population and by first testing the impact of the messages it is possible to develop materials that can effectively alter public health behaviours as desired.

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Appendix 1: Literature Review Search Strategy

A summary of the database searches that were performed during the process of conducting the review is set out below, with number of results in brackets.

Database Searches

Embase

1. exp tick (13436)
2. exp LYME DISEASE VACCINE or exp LYME DISEASE (10549)
3. exp tick borne disease (1550)
4. lyme.mp. (11807)
5. tick?.mp. (23159)
6. 1 or 2 or 3 or 4 or 5 (31193)
7. exp health education or exp public health (27030)
8. exp medical information or exp health behavior or exp public health or exp health promotion or exp attitude to health (352003)
9. leaflet.mp. (10137)
10. poster.mp. (2629)
11. campaign.mp. (16061)
12. psycholog?.mp. (144616)
13. (education or educational).mp. (723903)
14. 7 or 8 or 9 or 10 or 11 or 12 or 13 (1138165)
15. 6 and 14 (656)

Medline

1. exp Ticks (13821)
2. exp Lyme Disease Vaccines or exp Lyme Disease or exp Lyme Neuroborreliosis (7924)
3. exp Tick-Borne Diseases (22679)
4. lyme.mp. (9279)
5. tick?.mp. (21841)
6. 1 or 2 or 3 or 4 or 5 (36544)
7. exp Communication or exp Information Dissemination or exp Patient Education as Topic (370217)
8. exp Health Education or exp Health Knowledge, Attitudes, Practice or exp Health Promotion (195197)
9. leaflet.mp. (8954)
10. poster.mp. (1269)
11. campaign.mp. (13746)
12. psycholog?.mp. (206716)
13. (education or educational).mp. (518235)
14. 7 or 8 or 9 or 10 or 11 or 12 or 13 (1032881)
15. 6 and 14 (451)

PsycINFO

1. exp Lyme Disease (92)
2. lyme.mp. (187)
3. tick?.mp. (318)
4. 1 or 2 or 3 (472)
5. exp Communication or exp Risk Perception or exp Written Communication (151992)
6. risk communication.mp. (663)
7. exp Public Health or exp Behavior Change or exp Health Promotion or exp Health Education or exp Persuasive Communication or exp Prevention or exp Program Evaluation or exp Health Behavior (90528)
8. leaflet.mp. (315)
9. poster.mp. (684)
10. campaign.mp. (4107)
11. psycholog?.mp. (252003)
12. (education or educational).mp. (353877)
13. 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 (736669)
14. 4 and 13 (82)

ISI Web of Knowledge

1. tick? (20805)
2. lyme (15891)
3. tick borne disease (6381)
4. 1 or 2 or 3 (35905)
5. risk communication (25079)
6. health communication (80318)
7. leaflet (15391)
8. poster (>100000)
9. campaign (52851)
10. psycholog? (>100000)
11. education or educational (>100000)
12. 5 or 6 or 7 or 8 or 9 or 10 or 11 (>100000)
13. 4 and 12 (694)

Scopus

1. tick? (27101)
2. lyme (12373)
3. tick borne disease (2430)
4. 1 or 2 or 3 (35087)
5. risk communication (2286)
6. public health communication (120)
7. health communication (3198)
8. leaflet (16984)
9. poster (8624)

- 10. campaign (58815)
- 11. psycholog? (337299)
- 12. 5 or 6 or 7 or 8 or 9 or 10 or 11 (424961)
- 13. 4 and 12 (124)

Appendix 2: Behaviour Change Techniques Taxonomy

Taken from: Abraham, C., & Michie, S. (2007). A taxonomy of behavior change techniques used in interventions. *Health Psychology, 27*, 379-87.

Behaviour Change Technique Definitions

1. Provide general information on behaviour-health link

Information about the relationship between the behaviour and health – including susceptibility or factual risk and/or mortality information OR. health education material relevant to the behaviour. **NB** Check that any instance does not also involve techniques 2 or 3.

2. Provide information on consequences

Involves providing information focusing on what will happen if the person performs the behaviour including the **benefits and costs** of action or inaction. **NB** Check that any instance does not also involve techniques 1 or 3.

3. Provide information about others' approval

Involves information about what other people think about the reader's or target person's behaviour. It clarifies whether others will like, approve or disapprove of what the person is doing or will do. **NB** Check that any instance does not also involve techniques 1 or 3.

4. Prompt intention formation

Involves encouraging the person to set a general goal or make a behavioural resolution e.g., "I will take more exercise next week" would count as a prompt to intention formation. This is directed towards encouraging people to decide to change. **NB** This is distinguished from technique 10 by the general nature of the goal i.e., it does not involve planning exactly what will be done or when the behaviour or action sequence will be performed. Where the text only states that goal setting was used without specifying the detail of action planning involved then this would be an example of this technique (not technique 10)

5. Prompt barrier Identification

Think about potential barriers and plan ways of overcoming them. Barriers may include competing goals in specified situations. This may be described as "problem solving" and if it is problem solving in relation performance of the behaviour i.e., then it is an instance of this technique. **NB** Closely related to technique 10 but involves a focus on specific obstacles to performance. Techniques 5, 7 and 10 can be used independently or in combination – check for each separately.

6. Provide general encouragement

Involves praising or rewarding the person for effort or performance without making this contingent on specific behavioural performance; or "motivating" the person in an unspecified manner. This will include attempts to enhance self efficacy through argument or persuasion (e.g., telling someone they will be able to perform a behaviour). **NB** Check distinction with techniques 14 and 16.

7. Set graded tasks

Set the person easy-to-perform tasks, making them increasingly difficult until target behaviour is performed.

NB Although this might follow from technique 10, the key difference lies in planning to perform a sequence of preparatory actions or task components which *increase in difficulty over time* - as opposed to simply planning out a sequence of actions in detail.

8. Provide instruction

Involves *telling* the person *how* to perform a behaviour or preparatory behaviours. For example, providing individual face to face instructions, offering an instructional group class or providing “tips” on *how* to take action in text form. **NB** Check whether there are also instances of techniques 4, 5, 7, 9 or 10.

9. Model/ Demonstrate the behaviour

Involves *showing* the person how to correctly perform a behaviour e.g., face-to-face as in a group class or using video. **NB** This is distinct from just providing instruction (technique 8) because in “demonstration” the person is able to *observe* the behaviour being enacted. Techniques 8 and 9 may be used separately or together – check for this.

10. Prompt specific goal setting

Involves detailed planning of what the person will do including, at least, a very specific definition of the behaviour e.g., frequency (such as how many times a day/week), intensity (e.g., speed) or duration (e.g., for how long for). In addition, at least one of the following contexts i.e., where, when, how or with whom must be specified. This could include identification of sub-goals or preparatory behaviours and/or specific contexts in which the behaviour will be performed. **NB** Without clear illustration of this level of detail instances of “goal setting” should be regarded as applications of technique 4. Thus the terms “goal setting” or “personal plan” 4 are not enough to ensure inclusion of this technique. When specific goal setting is used this does not automatically imply technique 4. Both or either may be included in an intervention.

11. Prompt review of behavioural goals

Involves reconsideration of previously set goals/ intentions. In most cases this will follow previous goal setting and an attempt to act on those goals. **NB** Check that any instance does not also involve techniques 4, 7 or 10.

12. Prompt self-monitoring of behaviour

The person is asked to keep a record of specified behaviour/s. This could e.g., take the form of a diary or completing a questionnaire about their behaviour.

13. Provide feedback on performance

This involves either receiving data about recorded behaviour (e.g., following technique 12) or commenting on how well or badly a person has performed an action (e.g., identifying a discrepancy with a set goal – see techniques 4 and 10 – or a discrepancy in relation to the performance of others – note this could also involve technique 19). **NB** General praise which does not include comment on performance is included in technique 6.

14. Provide contingent rewards

This can include praise and encouragement as well as material rewards but the reward/ incentive must be explicitly linked to the achievement of specified goals i.e. the person receives the reward if they perform the specified behaviour (or preparatory behaviour) but not if they do not perform the behaviour. **NB** Check the distinction between this and techniques 6 and 13.

15. Teach to use prompts/ cues

Teach the person to identify environmental prompts which can be used to remind them to perform the behaviour. This could include times of day, particular contexts or elements of contexts which prompt them to perform the target behaviour. Note that this could be used independently or in conjunction with techniques 4 and 10..

16. Agree behavioural contract

Must involve agreement (e.g., signing) of an explicitly specifying behaviour so that there is a written record of the person's resolution witnessed by another.

17. Prompt practice

Prompt the person to rehearse and repeat the behaviour or preparatory behaviours numerous times. Note this will also include parts of the behaviour e.g., refusal skills in relation to quitting smoking. This could be described as "building habits or routines" but is still practice so long as the person is prompted to try the behaviour (or parts of it) during the intervention. **NB** If this is done in a group setting it will inevitably involve technique 19. Thus a group class in which people perform the behaviour or parts of the behaviour will include practice and opportunities for social comparison.

18. Use of follow up prompts

Involves sending letters, making telephone calls, visits or follow up meetings after the major part to the behaviour change intervention has been completed. If spaced contacts is an intrinsic part of the behaviour change intervention these in themselves do not count as follow up. **NB** This may (but does not need to) involve general encouragement i.e. include an instance of technique 6.

19. Provide opportunities for social comparison

This will most commonly be seen in the case of group practice (e.g., group classes) but could also be employed using detailed case studies in text or video or by pairing people as supports. It provides a setting in which processes such as social comparison could occur. Social support may also be encouraged in such settings and this would then involve technique 20. Group classes may also involve instruction (technique 8) demonstration (technique 9) and practice (technique 17). Check for these additional techniques.

20. Plan social support/ social change

Involves prompting the person to think about how others' could change their behaviour to offer him/her help and/or (instrumental) social support. This will also include provision of such support during the interventions e.g., setting up a "buddy" system or other forms of support. **NB** This could (but does not need to) involve technique 5 – where others' behaviour are perceived to be a key barrier to successful performance. Techniques 5 and 20 can be used independently or together.

21. Prompt identification as role model/ position advocate

Involves focusing on how the person may be an example to others and affect their behaviour e.g., being a good example to children. Also includes providing opportunities for participants to persuade others of the importance of adopting/ changing the behaviour. For example, giving a talk or writing a persuasive leaflet.

22. Prompt Self talk

Encourage the person to use talk to themselves (aloud or silently) before and during planned behaviours to encourage and support action.

23. Relapse prevention

Following an initial change help the person identify situations that increase the likelihood of returning to a risk behaviour or failing to perform a new health behaviour – and help them plan how to avoid or manage the situation so that new behavioural routines are maintained.

NB This may look like technique 5 but is distinct in that it occurs only after an initial change has taken place.

24. Stress management

This may involve a variety of specific techniques (e.g., progressive relaxation) which do not target the behaviour directly but seek to reduce anxiety and stress to facilitate the performance of the behaviour.

25. Motivational interviewing

This is a specific set of techniques involving prompting the person to provide self-motivating statements and evaluations of own behaviour to minimise resistance to change (includes motivational counselling). **NB** Normally this technique will be mentioned by name.

26. Time management

This includes any technique designed to help a person make time for the behaviour (e.g., how to fit it into a daily or weekly schedule). These techniques are not directed towards performance of target behaviour but rather seek to facilitate it by freeing up times when it could be performed. This technique may or may not be mentioned by name.

Appendix 3: Expert Interview Schedule

Initial explanation about the purpose of the interview and building of the mental model of the tick to Lyme disease pathway.

General mental model (e.g. radon) shown at this point so participants know what the aim is.

Begin by getting people to talk about their expertise with ticks – what is their field, what experiences have they had.

How a tick ends up on a human

- Risks posed by ticks
- How people come into contact with ticks: where are ticks found
- Possible tick control methods
 - o Any that are currently used in the UK
 - o Precautionary behaviours for the population
- Any misconceptions regarding ticks
- Ever been bitten before, if so, what action taken

How you end up with Lyme

- What to do if you're bitten by a tick
- Where do you get Lyme? Hotspots?
- Tick removal strategies
- How not to remove a tick and why
- Any check up necessary? Recommended action to take.

About Lyme disease

- Spread of Lyme disease: higher incidence but just more awareness?
- Lyme as a serious threat and why
- In US versus UK: same species? Same infection?
- Treatment difficulties
- How does Lyme testing work in the UK – certain locations?
- Symptoms
 - o GP recognition
 - o Patient recognition

Other: Public Health Communication, Disgust, etc.

(Mental Model of Lyme from book shown at this point)

- Barriers to altering public behaviour
- Messages public need to hear
- Any existing public health info (ticks or Lyme)
 - o Effectiveness or not and why
 - o How widely available – how have you come into contact with them
- Disgust as communication strategy
 - o View on effectiveness or not and why
- Any specialist info needed for professionals

Appendix 4: Public Interview Guide

Initial explanation about the purpose of the interview and how we are trying to build a model of the tick to Lyme disease pathway.

Begin by getting people to talk about their experience with ticks (potentially ranging from none to frequent).

The topics below are to be used as a guide of which topics need to be covered in the interview, but they do not need to be in any particular order.

How a tick ends up on a human

- Can you recognize a tick?
- How people come into contact with ticks: where are ticks found
- Possible tick control methods: are there ways that they can be avoided or protected against (do people know any of these already)
- Light coloured trousers:
 - o Would you do this? Why or why not?
- Tuck trousers into socks:
 - o Would you do this? Why or why not?
- Treat pets for ticks:
 - o Would you do this? Why or why not?
- Treat clothing with acaricide:
 - o Would you do this? Why or why not?
- Stick to cleared pathways / avoid vegetation:
 - o Would you do this? Why or why not?
- Which precautions do you prefer / think are most effective? Why? Confident you could perform these behaviours?
- Do these seem like suitable preventions? Why or why not?
- Would you need reminding to perform these behaviours? If so what would help?
- Does anyone you know take any precautions? If so which ones?
- How might you be encouraged to take precautions?
- Ever been bitten before, if so, what action taken?

How you end up with Lyme

- Have you or anyone you know ever developed Lyme or another tick-borne disease?
- How likely do you think you are to get Lyme...do you feel at risk? Are loved ones at risk? If you have kids do you check them for ticks?
- Do you know how to perform a tick check? Do you perform tick checks? Why or why not? How regularly? Effective?
- Tick removal strategies:
 - o Ever removed a tick? How?
 - o If not how do you think you should remove it?
 - o Do you have a specific removal device? Where did you get it? Useful?
 - o Can you / do you think you can remove it effectively? How could your confidence be increased?
- Any check up necessary?

About Lyme disease

- Have you heard of Lyme before? If so, what do you know about it? Where did you get that info?
- In your opinion what are consequences of tick bites / Lyme?
- What are the symptoms of Lyme? Do you feel confident in identifying them or identifying a tick bite? Why or why not? If no, what would help make it easier?

Other: Public Health Communication, Disgust, etc.

- Messages you want to hear or think are important
- Any existing public health info (ticks or Lyme) that you have come across
 - o Effectiveness or not and why?
 - o How widely available – how have you come into contact with them? Where?
- Do you find ticks disgusting? Why or why not? What is it about them (the blood, they burrow into the skin, etc.)
- If they are disgusting, would you take precautions? If so, which ones? Why?
- Knowing about ticks and Lyme, would you avoid rural areas or outdoor activities you are currently engaged in? If yes, could anything change this?
- Would you restrict where you kids play / outdoor activities?

Appendix 5: Web Survey Questionnaire

January 2012

We are a group of researchers from King's College London and the Health Protection Agency, interested in people's opinions about health-related issues. We would like to invite you to take part in a survey about this which should not take longer than 15 minutes to complete.

All of the information we collect in this survey will be kept in the strictest confidence and used for research purposes only. It will not be possible to identify any individual in the results.

If you take part, we will enter you into a prize draw for £200 as a thank you.

The survey can be completed anonymously. However if you would like to be entered into the prize draw you will be required to leave your email address.

I consent to the processing of my personal information for the purposes explained to me. I understand that such information will be treated in accordance with the terms of the Data Protection Act 1998. (tick 'yes' or 'no' – if no, survey automatically routes to end)

Background information

1. Have you been rambling or walking in any of the following UK locations? Select all that apply.
 - a) New Forest
 - b) Scottish Highlands
 - c) Dartmoor
 - d) Exmoor
 - e) South Downs
 - f) Thetford Forest
 - g) Lake District
 - h) Yorkshire Moors
 - i) Richmond Park
 - j) I have not been to any of the above locations

If option 'j' is selected, survey automatically routes to end.

2. Please select which, if any of these images, shows a tick. There may be more than one correct answer. The images are numbered as they appear here, so Option 1 is the top-most image and Option 5 is the bottom-most image.
 - a) Option 1
 - b) Option 2
 - c) Option 3
 - d) Option 4
 - e) Option 5

[After submitting their answer for question 2, participants are shown the correct tick images.]

3. Have you ever been bitten by a tick?
 - a) Definitely yes
 - b) Probably yes
 - c) Probably no
 - d) Definitely no
 - e) I don't know
4. To safely remove a tick you can: [participants can choose any combination of answers]
 - a) Pull off with tweezers
 - b) Pull off with your fingers
 - c) Cover with Vaseline
 - d) Cover with lighter fluid
 - e) Burn off with a cigarette
 - f) Wait for it to drop off itself
 - g) Cover it with salt
 - h) Other, please specify [space provided for text]

Behaviour measures

Please indicate how often you do each of the following while rambling or walking in **any** of the UK locations listed above. For each question, please say whether you do it: *Never (code as 1), almost never (2), about half the time (3), almost always (4), always (5).*

5. When rambling or walking in these areas I wear long trousers.
6. When rambling or walking in these areas I wear light coloured trousers
7. When rambling or walking in these areas I tuck my trousers into my socks.
8. When rambling or walking in these areas I stick to the pathways.
9. When rambling or walking in these areas I use an insect repellent on my clothes.
10. When rambling or walking in these areas I use an insect repellent on my skin.
11. While rambling or walking in these areas I check to see if any ticks are on **my clothes**.
12. While rambling or walking in the countryside I check to see if I have any ticks on **my body**.
13. After rambling or walking in the countryside I check to see if I have any ticks on **my body**.
14. **For participants who say always, almost always or about half the time for Q13.**
When checking for ticks, which areas of the body do you check and how? (Select all appropriate using: never (1), almost never (2), about half the time (3), almost always (4), always (4)).
 - a) Arms
 - b) Legs
 - c) Torso
 - d) Neck and scalp
 - e) Use a mirror
 - f) In the shower
 - g) Get someone else to help me check
 - h) Other (explain)

15. For participants who say almost never or never for Q13.

I do not check for ticks after rambling or walking in these areas because (Select all appropriate).

- a) Takes too much time
- b) I forget to do it
- c) It would be inconvenient
- d) I don't really need to
- e) I don't know how to do a check
- f) No one I know does it
- g) No reason to check for ticks
- h) Other (explain)

Predictor measures

Please indicate whether you: *Strongly disagree (code as 1), disagree (2), neither agree nor disagree (3), agree (4) or strongly agree (5).*

- 16. If a tick bit me I would feel confident about removing it myself
- 17. If a tick bit me I would know how to remove it
- 18. When out walking, what I do could determine whether or not I came into contact with ticks
- 19. Whether or not I get bitten by a tick when out walking would depend on me
- 20. Nothing I do will affect whether or not I get bitten by a tick when out walking
- 21. I have the power to influence whether or not I am bitten by a tick when out walking
- 22. Performing a tick check is too time consuming
- 23. I would normally forget to perform a tick check
- 24. I know the habitats where I can come into contact with ticks
- 25. When walking abroad I take precautions against ticks
- 26. Getting bitten by a tick would have major consequences on my life
- 27. I am likely to come into contact with ticks
- 28. I am likely to be bitten by a tick
- 29. There are effective measures that can prevent people from getting bitten by ticks
- 30. There is nothing that can be done to prevent people from getting bitten by ticks
- 31. Tick bites can be effectively treated
- 32. Ticks are disgusting
- 33. Having a tick biting me would be disgusting
- 34. I would be disgusted if I had to remove a tick from myself
- 35. Having a tick biting me would make me feel nauseous
- 36. I shudder when I think of ticks
- 37. If I saw a tick near me I would feel a strong instinct to avoid it

Ticks can pass on diseases, the most common of which is Lyme disease.

- 38. Getting Lyme disease is a serious condition
- 39. If I was bitten by a tick I would develop Lyme disease
- 40. There is enough information available about ticks and Lyme disease
- 41. I don't understand Lyme disease
- 42. I have a clear understanding of Lyme disease

Demographics

Please select the appropriate option for each question.

Are you:

Male

Female

How old are you:

Into which of the following categories would you place your total household income from all sources before tax and any other deductions:

Under £10,000

Over £10,000 but less than £20,000

Over £20,000 but less than £30,000

Over £30,000 but less than £40,000

Over £40,000 but less than £50,000

Over £50,000 but less than £75,000

Over £75,000

Don't know

Prefer not to say

Which, if any, is the highest educational or professional qualification you have obtained:

GCSE / O-level / CSE

Vocational qualifications (=NVQ1+2)

A-level or equivalent (=NVQ3)

Bachelor Degree or equivalent (=NVQ4)

Masters / PhD or equivalent

Other

No formal qualifications

Still studying

Don't know

Which one of these ethnic groups would you describe yourself as belonging to?

WHITE – British

WHITE – Irish

WHITE – Any other white background

ASIAN OR ASIAN BRITISH – Indian

ASIAN OR ASIAN BRITISH – Pakistani

ASIAN OR ASIAN BRITISH – Bangladeshi

ASIAN OR ASIAN BRITISH – Any other Asian background

BLACK OR BLACK BRITISH – Caribbean

BLACK OR BLACK BRITISH – African

BLACK OR BLACK BRITISH – Any other background

MIXED – White and Black Caribbean

MIXED – White and Black African

MIXED – White and Asian

MIXED – Any other mixed background

CHINESE OR OTHER ETHNIC GROUP – Chinese

CHINESE OR OTHER ETHNIC GROUP – Any other background

Prefer not to answer

If you would like to be entered into the prize draw for £200 please enter your email address below.

Appendix 6: Psychological variable scores.

Please indicate whether you strongly disagree, disagree, neither agree nor disagree, agree or strongly agree with each of these statements:	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
If a tick bit me I would feel confident about removing it myself	46 (13.3%)	117 (33.9%)	45 (13.0%)	107 (31.0%)	30 (8.7%)
If a tick bit me I would know how to remove it	54 (15.7%)	102 (29.6%)	51 (14.8%)	112 (32.5%)	26 (7.5%)
When out walking, what I do could determine whether or not I came into contact with ticks	16 (4.6%)	47 (13.6%)	71 (20.6%)	168 (48.7%)	43 (12.5%)
Whether or not I get bitten by a tick when out walking would depend on me	18 (5.2%)	94 (27.3%)	142 (41.2%)	83 (24.1%)	8 (2.3%)
Nothing I do will affect whether or not I get bitten by a tick when out walking	73 (21.2%)	204 (59.1%)	51 (14.8%)	16 (4.6%)	1 (0.3%)
I have the power to influence whether or not I am bitten by a tick when out walking	17 (4.9%)	37 (10.7%)	78 (22.6%)	176 (51.0%)	37 (10.7%)
Checking for ticks is too time consuming	26 (7.5%)	150 (43.5%)	107 (31.0%)	58 (16.8%)	20 (1.2%)
I would normally forget to check for ticks	13 (3.8%)	52 (15.1%)	40 (11.6%)	151 (43.8%)	89 (25.8%)
I know the habitats where I can come into contact with ticks	79 (22.9%)	106 (30.7%)	51 (14.8%)	99 (28.7%)	10 (2.9%)
When walking abroad I take precautions against ticks	74 (21.5%)	129 (37.4%)	59 (17.1%)	64 (18.6%)	19 (5.5%)
Getting bitten by a tick would have major consequences on my life	39 (11.3%)	123 (35.7%)	122 (35.4%)	53 (15.4%)	8 (2.3%)
I am likely to come into contact with ticks	15 (4.4%)	114 (33.0%)	96 (27.8%)	107 (31.0%)	13 (3.8%)
I am likely to be bitten by a tick	13 (3.8%)	142 (41.2%)	123 (35.7%)	59 (17.1%)	8 (2.3%)
There are effective measures that can prevent people from getting bitten by ticks	2 (0.6%)	15 (4.4%)	84 (24.4%)	212 (61.5%)	32 (9.3%)
There is nothing that can be done to prevent people from getting bitten by ticks	71 (20.6%)	197 (57.1%)	65 (18.8%)	12 (3.5%)	0 (0.0%)
Tick bites can be effectively treated	2 (0.6%)	13 (3.8%)	89 (25.8%)	200 (58.0%)	41 (11.9%)
Ticks are disgusting	11 (3.2%)	40 (11.6%)	104 (30.1%)	127 (36.8%)	63 (18.3%)
Having a tick biting me would be disgusting	12 (3.5%)	51 (14.8%)	84 (24.4%)	137 (39.7%)	61 (17.7%)
I would be disgusted if I had to remove a tick from myself	35 (10.1%)	113 (32.8%)	64 (18.6%)	95 (27.5%)	38 (11.0%)
Having a tick biting me would make me feel nauseous	61 (17.7%)	136 (39.4%)	69 (20.0%)	58 (16.8%)	21 (6.1%)
I shudder when I think of ticks	61 (17.7%)	129 (37.4%)	62 (18.0%)	70 (20.3%)	23 (6.7%)
If I saw a tick near me I would feel a strong instinct to avoid it	14 (4.1%)	34 (9.9%)	56 (16.2%)	162 (47.0%)	79 (22.9%)
Getting Lyme disease is a serious condition	0 (0.0%)	4 (1.2%)	49 (14.2%)	138 (40.1%)	153 (44.5%)
If I was bitten by a tick I would develop Lyme disease	11 (3.2%)	120 (34.9%)	187 (54.4%)	24 (7.0%)	2 (0.6%)
I think there is enough information available about ticks and Lyme disease	74 (21.5%)	156 (45.4%)	65 (18.9%)	42 (12.2%)	7 (2.0%)
I don't understand Lyme disease	10 (2.9%)	66 (19.2%)	62 (18.0%)	146 (42.4%)	60 (17.4%)
I have a clear understanding of Lyme disease	74 (21.5%)	146 (42.4%)	55 (16.0%)	60 (17.4%)	9 (2.6%)

Appendix 7: Associations between demographic variables and tick checking of clothes while walking

Demographic Variable	No (%) of participants	No (%) performing tick check of clothes at least half the time while walking	χ^2	p
Gender			0.02	0.90
Male	97 (28.0)	15 (15.5)		
Female	246 (72.0)	35 (14.2)		
Age			1.70	0.79
18-24	92 (27.0)	11 (12.0)		
25-34	132 (38.0)	23 (17.4)		
35-44	57 (17.0)	7 (12.3)		
45-54	44 (13.0)	6 (13.6)		
55+	18 (5.0)	3 (16.7)		
Income			1.77	0.62
<10,000 - £30,000	119 (34.7)	21 (17.6)		
Over £30,000 but less than £50,000	81 (23.6)	11 (13.6)		
Over £50,000	97 (28.3)	13 (13.4)		
Don't know / prefer not to say	32 (9.3)	3 (9.4)		
Qualifications			1.35	0.25
GCSE / vocational / A-level / still studying / other	65 (19.0)	6 (9.2)		
Bachelor degree / Masters / PhD	278 (81.0)	44 (15.8)		
Ethnicity			1.96	0.38
White (British, Irish, any other white background)	305 (89.0)	47 (15.4)		
Any other ethnicity*	31 (9.0)	3 (9.7)		
Prefer not to say	7 (2.0)	0 (0.0)		

*includes the following ethnicity categories: Asian or Asian British - Indian, Pakistani, Bangladeshi, Any other Asian background; Black or Black British – Caribbean, African, Any other Black background; Mixed – White and Black Caribbean, White and Black African, White and Asian, Any other mixed background; Chinese or other ethnic group – Chinese, Any other background

Appendix 8: Associations between demographic variables and tick check of body while walking

Demographic Variable	No (%) of participants	No (%) performing tick check of body at least half the time while walking	χ^2	p
Gender			0.04	0.84
Male	96 (28.0)	14 (14.6)		
Female	246 (72.0)	32 (13.0)		
Age			4.35	0.36
18-24	92 (27.0)	12 (13.0)		
25-34	131 (38.0)	16 (12.2)		
35-44	57 (17.0)	9 (15.8)		
45-54	44 (13.0)	4 (9.1)		
55+	18 (5.0)	5 (27.8)		
Income			2.85	0.42
<10,000 - £30,000	118 (36.0)	18 (15.3)		
Over £30,000 but less than £50,000	81 (24.0)	7 (8.6)		
Over £50,000	97 (30.0)	15 (15.5)		
Don't know / prefer not to say	32 (10.0)	6 (18.8)		
Qualifications			0.01	0.92
GCSE / vocational / A-level / still studying / other	65 (19.0)	8 (12.3)		
Bachelor degree / Masters / PhD	277 (81.0)	38 (13.7)		
Ethnicity			2.52	0.28
White (British, Irish, any other white background)	305 (89.0)	44 (14.4)		
Any other ethnicity*	30 (9.0)	2 (6.7)		
Prefer not to say	7 (2.0)	0 (0.0)		

*includes the following ethnicity categories: Asian or Asian British - Indian, Pakistani, Bangladeshi, Any other Asian background; Black or Black British – Caribbean, African, Any other Black background; Mixed – White and Black Caribbean, White and Black African, White and Asian, Any other mixed background; Chinese or other ethnic group – Chinese, Any other background

Appendix 9: Associations between demographic variables and wearing trousers while walking

Demographic Variable	No (%) of participants	No (%) wearing trousers at least half the time while walking	χ^2	p
Gender			0.00	1.00
Male	97 (28.0)	92 (94.8)		
Female	246 (72.0)	232 (94.3)		
Age			5.58	0.23
18-24	92 (27.0)	83 (90.2)		
25-34	132 (38.0)	127 (96.2)		
35-44	57 (17.0)	55 (96.5)		
45-54	44 (13.0)	41 (93.2)		
55+	18 (5.0)	18 (93.2)		
Income			3.90	0.27
<10,000 - £30,000	119 (36.0)	115 (96.6)		
Over £30,000 but less than £50,000	81 (24.0)	76 (93.8)		
Over £50,000	97 (30.0)	88 (90.7)		
Don't know / prefer not to say	32 (10.0)	31 (96.9)		
Qualifications			0.29	0.59
GCSE / vocational / A-level / still studying / other	65 (19.0)	60 (92.3)		
Bachelor degree / Masters / PhD	278 (81.0)	264 (95.0)		
Ethnicity			8.93	0.01
White (British, Irish, any other white background)	305 (89.0)	292 (95.7)		
Any other ethnicity*	31 (9.0)	25 (80.6)		
Prefer not to say	7 (2.0)	7 (100.0)		

*includes the following ethnicity categories: Asian or Asian British - Indian, Pakistani, Bangladeshi, Any other Asian background; Black or Black British – Caribbean, African, Any other Black background; Mixed – White and Black Caribbean, White and Black African, White and Asian, Any other mixed background; Chinese or other ethnic group – Chinese, Any other background

Appendix 10: Associations between demographic variables and wearing light coloured trousers while walking

Demographic Variable	No (%) of participants	No (%) wearing light coloured trousers at least half the time while walking	X ²	p
Gender			9.98	0.002
Male	97 (28.0)	47 (48.5)		
Female	246 (72.0)	73 (29.7)		
Age			12.38	0.02
18-24	92 (27.0)	23 (25.0)		
25-34	132 (38.0)	42 (31.8)		
35-44	57 (17.0)	24 (42.1)		
45-54	44 (13.0)	23 (52.3)		
55+	18 (5.0)	8 (44.4)		
Income			7.28	0.06
<10,000 - £30,000	119 (36.0)	34 (28.6)		
Over £30,000 but less than £50,000	81 (24.0)	32 (39.5)		
Over £50,000	97 (30.0)	34 (35.1)		
Don't know / prefer not to say	32 (10.0)	17 (53.1)		
Qualifications			0.00	1.00
GCSE / vocational / A-level / still studying / other	65 (19.0)	23 (35.4)		
Bachelor degree / Masters / PhD	278 (81.0)	97 (34.9)		
Ethnicity			1.43	0.49
White (British, Irish, any other white background)	305 (89.0)	110 (36.1)		
Any other ethnicity*	31 (9.0)	8 (25.8)		
Prefer not to say	7 (2.0)	2 (28.6)		

*includes the following ethnicity categories: Asian or Asian British - Indian, Pakistani, Bangladeshi, Any other Asian background; Black or Black British – Caribbean, African, Any other Black background; Mixed – White and Black Caribbean, White and Black African, White and Asian, Any other mixed background; Chinese or other ethnic group – Chinese, Any other background

Appendix 11: Associations between demographic variables and tucking trousers into socks while walking

Demographic Variable	No (%) of participants	No (%) tucking trousers into socks at least half the time while walking	χ^2	p
Gender			4.40	0.04
Male	97 (28.0)	12 (12.4)		
Female	246 (72.0)	57 (23.2)		
Age			3.21	0.52
18-24	92 (27.0)	21 (22.8)		
25-34	132 (38.0)	25 (18.9)		
35-44	57 (17.0)	10 (17.5)		
45-54	44 (13.0)	7 (15.9)		
55+	18 (5.0)	6 (33.3)		
Income			5.90	0.12
<10,000 - £30,000	119 (36.0)	32 (26.9)		
Over £30,000 but less than £50,000	81 (24.0)	12 (14.8)		
Over £50,000	97 (30.0)	16 (16.5)		
Don't know / prefer not to say	32 (10.0)	8 (25.0)		
Qualifications			0.29	0.59
GCSE / vocational / A-level / still studying / other	65 (19.0)	11 (16.9)		
Bachelor degree / Masters / PhD	278 (81.0)	58 (20.9)		
Ethnicity			4.19	0.12
White (British, Irish, any other white background)	305 (89.0)	65 (21.3)		
Any other ethnicity*	31 (9.0)	2 (6.5)		
Prefer not to say	7 (2.0)	2 (28.6)		

*includes the following ethnicity categories: Asian or Asian British - Indian, Pakistani, Bangladeshi, Any other Asian background; Black or Black British - Caribbean, African, Any other Black background; Mixed - White and Black Caribbean, White and Black African, White and Asian, Any other mixed background; Chinese or other ethnic group - Chinese, Any other background

Appendix 12: Associations between demographic variables and sticking to clear pathways while walking

Demographic Variable	No (%) of participants	No (%) sticking to clear pathways at least half the time while walking	X ²	p
Gender			1.64	0.20
Male	97 (28.0)	85 (87.6)		
Female	246 (72.0)	228 (92.7)		
Age			4.45	0.35
18-24	92 (27.0)	80 (87.0)		
25-34	132 (38.0)	121 (91.7)		
35-44	57 (17.0)	55 (96.5)		
45-54	44 (13.0)	41 (93.2)		
55+	18 (5.0)	16 (88.9)		
Income			4.42	0.22
<10,000 - £30,000	119 (36.0)	108 (90.8)		
Over £30,000 but less than £50,000	81 (24.0)	71 (87.8)		
Over £50,000	97 (30.0)	89 (91.8)		
Don't know / prefer not to say	32 (10.0)	32 (100.0)		
Qualifications			0.008	0.93
GCSE / vocational / A-level / still studying / other	65 (19.0)	60 (92.3)		
Bachelor degree / Masters / PhD	278 (81.0)	253 (91.0)		
Ethnicity			0.71	0.70
White (British, Irish, any other white background)	305 (89.0)	278 (91.1)		
Any other ethnicity*	31 (9.0)	28 (90.3)		
Prefer not to say	7 (2.0)	7 (100.0)		

*includes the following ethnicity categories: Asian or Asian British - Indian, Pakistani, Bangladeshi, Any other Asian background; Black or Black British – Caribbean, African, Any other Black background; Mixed – White and Black Caribbean, White and Black African, White and Asian, Any other mixed background; Chinese or other ethnic group – Chinese, Any other background

Appendix 13: Associations between demographic variables and using repellent on clothes while walking

Demographic Variable	No (%) of participants	No (%) using repellent on clothes at least half the time while walking	χ^2	p
Gender			0.05	0.82
Male	97 (28.0)	8 (8.2)		
Female	246 (72.0)	24 (9.8)		
Age			4.69	0.32
18-24	92 (27.0)	4 (4.3)		
25-34	132 (38.0)	14 (10.6)		
35-44	57 (17.0)	7 (12.3)		
45-54	44 (13.0)	4 (9.1)		
55+	18 (5.0)	3 (16.7)		
Income			0.42	0.94
<10,000 - £30,000	119 (36.0)	10 (8.4)		
Over £30,000 but less than £50,000	81 (24.0)	9 (11.1)		
Over £50,000	97 (30.0)	9 (9.3)		
Don't know / prefer not to say	32 (10.0)	3 (9.4)		
Qualifications			0.55	0.46
GCSE / vocational / A-level / still studying / other	65 (19.0)	4 (6.2)		
Bachelor degree / Masters / PhD	278 (81.0)	28 (10.1)		
Ethnicity			1.12	0.57
White (British, Irish, any other white background)	305 (89.0)	30 (9.8)		
Any other ethnicity*	31 (9.0)	2 (6.5)		
Prefer not to say	7 (2.0)	0 (0.0)		

*includes the following ethnicity categories: Asian or Asian British - Indian, Pakistani, Bangladeshi, Any other Asian background; Black or Black British - Caribbean, African, Any other Black background; Mixed - White and Black Caribbean, White and Black African, White and Asian, Any other mixed background; Chinese or other ethnic group - Chinese, Any other background

Appendix 14: Associations between demographic variables and using repellent on skin while walking

Demographic Variable	No (%) of participants	No (%) using repellent on skin at least half the time while walking	χ^2	p
Gender			1.63	0.20
Male	97 (28.0)	15 (15.5)		
Female	246 (72.0)	55 (22.4)		
Age			6.31	0.17
18-24	92 (27.0)	16 (17.4)		
25-34	132 (38.0)	32 (24.2)		
35-44	57 (17.0)	6 (10.5)		
45-54	44 (13.0)	11 (25.0)		
55+	18 (5.0)	5 (27.8)		
Income			2.63	0.45
<10,000 - £30,000	119 (36.0)	20 (16.8)		
Over £30,000 but less than £50,000	81 (24.0)	19 (23.5)		
Over £50,000	97 (30.0)	19 (19.6)		
Don't know / prefer not to say	32 (10.0)	9 (28.1)		
Qualifications			2.65	0.10
GCSE / vocational / A-level / still studying / other	65 (19.0)	8 (12.3)		
Bachelor degree / Masters / PhD	278 (81.0)	62 (22.3)		
Ethnicity			2.64	0.27
White (British, Irish, any other white background)	305 (89.0)	66 (21.6)		
Any other ethnicity*	31 (9.0)	3 (9.7)		
Prefer not to say	7 (2.0)	1 (14.3)		

*includes the following ethnicity categories: Asian or Asian British - Indian, Pakistani, Bangladeshi, Any other Asian background; Black or Black British – Caribbean, African, Any other Black background; Mixed – White and Black Caribbean, White and Black African, White and Asian, Any other mixed background; Chinese or other ethnic group – Chinese, Any other background

Appendix 15: Logistic regression predicting wearing long trousers while walking.

Predictor Variable (example statement)	Mean (SD) score ^a , No of participants	p	Odds ratio (95% CI) for wearing long trousers
Disgust (Ticks are disgusting)	3.16 (0.87), 343	0.86	1.05 (0.61 to 1.78)
Efficacy (Nothing can be done to prevent people getting bitten by ticks)	3.85 (0.64), 343	0.22	0.61 (0.28 to 1.33)
Control (Whether or not I get bitten would depend on me)	3.47 (0.70), 343	0.20	0.63 (0.31 to 1.28)
Getting bitten would have serious consequences on my life	2.91 (0.90), 343	0.23	1.36 (0.82 to 2.26)
What I do could determine whether or not I came into contact with ticks	3.51 (1.03), 343	0.097	0.64 (0.37 to 1.09)
Checking for ticks is too time consuming	2.61 (0.90), 343	0.51	1.20 (0.70 to 2.04)
Tick bites can be effectively treated	3.76 (0.73), 343	0.42	0.76 (0.39 to 1.48)
If I was bitten by a tick I would get Lyme disease	2.67 (0.68), 343	0.80	1.09 (0.55 to 2.16)
There is enough information available about ticks and Lyme disease	2.27 (1.00), 343	0.78	1.07 (0.67 to 1.72)
Removal confidence (If a tick bit me I would know how to remove it)	2.87 (1.15), 343	0.53	1.14 (0.76 to 1.70)
Likelihood (I am likely to be bitten by a tick)	2.85 (0.87), 343	0.10	1.59 (0.91 to 2.79)
Knowledge (I don't understand Lyme disease)	2.43 (1.04), 343	0.02	2.03 (1.15 to 3.57)
I would normally forget to check for ticks	3.74 (1.11), 343	0.40	0.82 (0.52 to 1.30)
I know tick habitats	2.57 (1.21), 343	0.02	1.76 (1.11 to 2.79)
I take precautions against ticks when I'm abroad	2.49 (1.17), 343	0.14	1.39 (0.89 to 2.17)
Lyme disease is a serious condition	4.28 (0.75), 343	0.30	1.37 (0.76 to 2.46)

^aScores range from 1 (strongly disagree) to 5 (strongly agree)

Appendix 16: Logistic regression predicting wearing light coloured trousers while walking.

Predictor Variable (example statement)	Mean (SD) score ^a , No of participants	p	Odds ratio (95% CI) for wearing light coloured trousers
Disgust (Ticks are disgusting)	3.16 (0.87), 343	0.01	0.72 (0.55 to 0.93)
Efficacy (Nothing can be done to prevent people getting bitten by ticks)	3.85 (0.64), 343	0.72	1.07 (0.75 to 1.51)
Control (Whether or not I get bitten would depend on me)	3.47 (0.70), 343	0.03	1.45 (1.04 to 2.02)
Getting bitten would have serious consequences on my life	2.91 (0.90), 343	0.09	1.22 (0.97 to 1.55)
What I do could determine whether or not I came into contact with ticks	3.51 (1.03), 343	0.33	1.11 (0.90 to 1.39)
Checking for ticks is too time consuming	2.61 (0.90), 343	0.33	0.88 (0.69 to 1.13)
Tick bites can be effectively treated	3.76 (0.73), 343	0.25	1.20 (0.88 to 1.64)
If I was bitten by a tick I would get Lyme disease	2.67 (0.68), 343	0.28	0.84 (0.60 to 1.16)
There is enough information available about ticks and Lyme disease	2.27 (1.00), 343	0.50	0.93 (0.74 to 1.16)
Removal confidence (If a tick bit me I would know how to remove it)	2.87 (1.15), 343	0.38	1.09 (0.90 to 1.32)
Likelihood (I am likely to be bitten by a tick)	2.85 (0.87), 343	0.003	1.48 (1.14 to 1.92)
Knowledge (I don't understand Lyme disease)	2.43 (1.04), 343	0.09	1.20 (0.97 to 1.48)
I would normally forget to check for ticks	3.74 (1.11), 343	0.44	0.93 (0.76 to 1.13)
I know tick habitats	2.57 (1.21), 343	0.04	1.22 (1.01 to 1.46)
I take precautions against ticks when I'm abroad	2.49 (1.17), 343	0.18	1.14 (0.94 to 1.37)
Lyme disease is a serious condition	4.28 (0.75), 343	0.0005	1.79 (1.29 to 2.48)

^aScores range from 1 (strongly disagree) to 5 (strongly agree)

Appendix 17: Logistic regression predicting tucking trousers into socks when walking.

Predictor Variable (example statement)	Mean (SD) score ^a , No of participants	p	Odds ratio (95% CI) for tucking trousers into socks
Disgust (Ticks are disgusting)	3.16 (0.87), 343	0.45	1.12 (0.82 to 1.51)
Efficacy (Nothing can be done to prevent people getting bitten by ticks)	3.85 (0.64), 343	0.81	0.95 (0.63 to 1.44)
Control (Whether or not I get bitten would depend on me)	3.47 (0.70), 343	0.42	1.17 (0.80 to 1.72)
Getting bitten would have serious consequences on my life	2.91 (0.90), 343	0.40	1.13 (0.86 to 1.49)
What I do could determine whether or not I came into contact with ticks	3.51 (1.03), 343	0.35	0.89 (0.69 to 1.14)
Checking for ticks is too time consuming	2.61 (0.90), 343	0.24	0.83 (0.62 to 1.13)
Tick bites can be effectively treated	3.76 (0.73), 343	0.05	0.70 (0.49 to 1.00)
If I was bitten by a tick I would get Lyme disease	2.67 (0.68), 343	0.73	1.07 (0.73 to 1.58)
There is enough information available about ticks and Lyme disease	2.27 (1.00), 343	0.99	1.00 (0.77 to 1.31)
Removal confidence (If a tick bit me I would know how to remove it)	2.87 (1.15), 343	0.42	1.10 (0.87 to 1.38)
Likelihood (I am likely to be bitten by a tick)	2.85 (0.87), 343	0.90	0.98 (0.72 to 1.32)
Knowledge (I don't understand Lyme disease)	2.43 (1.04), 343	0.19	1.18 (0.92 to 1.52)
I would normally forget to check for ticks	3.74 (1.11), 343	0.003	0.71 (0.56 to 0.89)
I know tick habitats	2.57 (1.21), 343	0.004	1.39 (1.11 to 1.74)
I take precautions against ticks when I'm abroad	2.49 (1.17), 343	0.001	1.45 (1.16 to 1.81)
Lyme disease is a serious condition	4.28 (0.75), 343	0.31	1.21 (0.84 to 1.75)

^aScores range from 1 (strongly disagree) to 5 (strongly agree)

Appendix 18: Logistic regression predicting sticking to clear pathways when walking.

Predictor Variable (example statement)	Mean (SD) score ^a , No of participants	p	Odds ratio (95% CI) for sticking to clear pathways
Disgust (Ticks are disgusting)	3.16 (0.87), 343	0.70	0.92 (0.60 to 1.41)
Efficacy (Nothing can be done to prevent people getting bitten by ticks)	3.85 (0.64), 343	0.65	0.87 (0.48 to 1.59)
Control (Whether or not I get bitten would depend on me)	3.47 (0.70), 343	0.78	0.93 (0.54 to 1.60)
Getting bitten would have serious consequences on my life	2.91 (0.90), 343	0.96	0.99 (0.67 to 1.47)
What I do could determine whether or not I came into contact with ticks	3.51 (1.03), 343	0.81	1.05 (0.73 to 1.50)
Checking for ticks is too time consuming	2.61 (0.90), 343	0.86	0.96 (0.64 to 1.46)
Tick bites can be effectively treated	3.76 (0.73), 343	0.11	0.63 (0.36 to 1.11)
If I was bitten by a tick I would get Lyme disease	2.67 (0.68), 343	0.02	1.92 (1.09 to 3.37)
There is enough information available about ticks and Lyme disease	2.27 (1.00), 343	0.36	0.85 (0.59 to 1.21)
Removal confidence (If a tick bit me I would know how to remove it)	2.87 (1.15), 343	0.29	0.84 (0.61 to 1.17)
Likelihood (I am likely to be bitten by a tick)	2.85 (0.87), 343	0.56	0.88 (0.58 to 1.35)
Knowledge (I don't understand Lyme disease)	2.43 (1.04), 343	0.29	1.23 (0.84 to 1.79)
I would normally forget to check for ticks	3.74 (1.11), 343	0.71	1.06 (0.76 to 1.48)
I know tick habitats	2.57 (1.21), 343	0.97	1.01 (0.74 to 1.37)
I take precautions against ticks when I'm abroad	2.49 (1.17), 343	0.97	0.99 (0.72 to 1.37)
Lyme disease is a serious condition	4.28 (0.75), 343	0.92	1.03 (0.62 to 1.69)

^aScores range from 1 (strongly disagree) to 5 (strongly agree)

Appendix 19: Logistic regression predicting using an insect repellent on clothes while walking.

Predictor Variable (example statement)	Mean (SD) score ^a , No of participants	p	Odds ratio (95% CI) for using repellent on clothes
Disgust (Ticks are disgusting)	3.16 (0.87), 343	0.86	0.96 (0.63 to 1.46)
Efficacy (Nothing can be done to prevent people getting bitten by ticks)	3.85 (0.64), 343	0.05	1.89 (1.00 to 3.51)
Control (Whether or not I get bitten would depend on me)	3.47 (0.70), 343	0.36	1.28 (0.75 to 2.20)
Getting bitten would have serious consequences on my life	2.91 (0.90), 343	0.55	1.12 (0.77 to 1.64)
What I do could determine whether or not I came into contact with ticks	3.51 (1.03), 343	0.23	1.27 (0.86 to 1.86)
Checking for ticks is too time consuming	2.61 (0.90), 343	0.03	0.62 (0.39 to 0.96)
Tick bites can be effectively treated	3.76 (0.73), 343	0.24	1.37 (0.81 to 2.33)
If I was bitten by a tick I would get Lyme disease	2.67 (0.68), 343	0.50	0.83 (0.49 to 1.42)
There is enough information available about ticks and Lyme disease	2.27 (1.00), 343	0.55	1.12 (0.78 to 1.59)
Removal confidence (If a tick bit me I would know how to remove it)	2.87 (1.15), 343	0.01	1.61 (1.15 to 2.26)
Likelihood (I am likely to be bitten by a tick)	2.85 (0.87), 343	0.14	1.37 (0.90 to 2.07)
Knowledge (I don't understand Lyme disease)	2.43 (1.04), 343	0.03	1.46 (1.04 to 2.04)
I would normally forget to check for ticks	3.74 (1.11), 343	0.0005	0.46 (0.34 to 0.64)
I know tick habitats	2.57 (1.21), 343	0.0005	1.96 (1.39 to 2.77)
I take precautions against ticks when I'm abroad	2.49 (1.17), 343	0.0005	1.88 (1.37 to 2.57)
Lyme disease is a serious condition	4.28 (0.75), 343	0.14	1.51 (0.88 to 2.59)

^aScores range from 1 (strongly disagree) to 5 (strongly agree)

Appendix 20: Logistic regression predicting using an insect repellent on skin while walking.

Predictor Variable (example statement)	Mean (SD) score ^a , No of participants	p	Odds ratio (95% CI) for using repellent on skin
Disgust (Ticks are disgusting)	3.16 (0.87), 343	0.67	1.07 (0.79 to 1.44)
Efficacy (Nothing can be done to prevent people getting bitten by ticks)	3.85 (0.64), 343	0.14	1.38 (0.90 to 2.12)
Control (Whether or not I get bitten would depend on me)	3.47 (0.70), 343	0.08	1.42 (0.95 to 2.10)
Getting bitten would have serious consequences on my life	2.91 (0.90), 343	0.54	1.09 (0.83 to 1.43)
What I do could determine whether or not I came into contact with ticks	3.51 (1.03), 343	0.16	0.84 (0.65 to 1.08)
Checking for ticks is too time consuming	2.61 (0.90), 343	0.05	0.73 (0.54 to 0.99)
Tick bites can be effectively treated	3.76 (0.73), 343	0.41	0.86 (0.60 to 1.23)
If I was bitten by a tick I would get Lyme disease	2.67 (0.68), 343	0.85	0.96 (0.65 to 1.42)
There is enough information available about ticks and Lyme disease	2.27 (1.00), 343	0.77	0.96 (0.74 to 1.25)
Removal confidence (If a tick bit me I would know how to remove it)	2.87 (1.15), 343	0.82	1.03 (0.82 to 1.29)
Likelihood (I am likely to be bitten by a tick)	2.85 (0.87), 343	0.80	0.96 (0.71 to 1.30)
Knowledge (I don't understand Lyme disease)	2.43 (1.04), 343	0.32	1.13 (0.88 to 1.47)
I would normally forget to check for ticks	3.74 (1.11), 343	0.002	0.70 (0.56 to 0.88)
I know tick habitats	2.57 (1.21), 343	0.19	1.16 (0.93 to 1.44)
I take precautions against ticks when I'm abroad	2.49 (1.17), 343	0.008	1.35 (1.08 to 1.68)
Lyme disease is a serious condition	4.28 (0.75), 343	0.33	1.20 (0.83 to 1.72)

^aScores range from 1 (strongly disagree) to 5 (strongly agree)

Appendix 21: New Forest Leaflet

Signs and Symptoms of Lyme Disease

Symptoms usually start a few days to several weeks after being bitten. The first sign is often a pink or red rash (erythema migrans) around the site of the bite. It can gradually spread to form a large circle or patch up to 50-75 centimetres (20-30 inches) diameter if left untreated. It is not usually raised, itchy or painful and clears up rapidly with antibiotic treatment. Sometimes the rash may be very faint, and it can also be difficult to see on darker skins. Rashes appearing within a few hours of a tick bite are not caused by Lyme disease, but could be allergic reactions or infections from common skin organisms. Flu-like symptoms may occur, with headaches, chills, tiredness, muscle pains, joint aches and fever. These symptoms could last several weeks without treatment, but usually settle quickly with correct antibiotic treatment. More serious complications sometimes develop weeks or months after an infected bite in patients who did not receive early treatment. These include: facial palsy; pain, tingling or loss of sensation in the arms, legs or trunk; and joint pains. Some patients may have been unaware of a tick bite or rash and the diagnosis of Lyme disease could be delayed or missed because of lack of recognition of their risk.

Treatment

Early treatment with recommended antibiotics is highly effective and should prevent complications developing. Longstanding infection may require longer courses or intravenous antibiotics, so early recognition and treatment is important.

Life cycle of the Deer Tick (*Ixodes ricinus*)

The relative size of the animals (including Man) approximates their significance as hosts for the different tick life cycle stages in a typical woodland habitat. Larvae rarely carry *Borrelia* and their bites are not a significant risk.

The life cycle usually takes 2-3 years. Although the peak feeding time is late spring/early summer with a lesser peak in autumn, tick activity (and the risk of tick bites) can extend beyond these periods in favourable weather conditions.

Useful websites:
 European Union Concerted Action on Lyme Borreliosis (EUCALB): www.vie.dls.strath.ac.uk/vie/LymeEU/leaflet.htm
 Centers for Disease Control and Prevention website: www.cdc.gov/ncidod/dvbid/lyme/index.htm
 Health Protection Agency: www.hpa.org.uk

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New Forest DISTRICT COUNCIL

Just a Tick ...

Tick Bites and Lyme Disease

Lyme disease, also called Lyme borreliosis, is an illness caused by the bacterium *Borrelia burgdorferi*, which lives in the gut of some ticks. Most ticks do not carry the bacteria, but infection could be passed on to people bitten by infected ticks. To be safe you should assume that any tick bite is potentially infectious. Infected ticks are found in many parts of the country, including the New Forest, East Anglia, West Country, Welsh Uplands and the Scottish Highlands. They also occur in other parts of Europe and North America.

What to look for

Ticks are tiny spider-like creatures found in grassy or wooded areas. They attach themselves to passing animals (small and large domestic and wild animals, depending on the particular stage of the tick's life-cycle) and people, and then actively crawl about until they find a suitable site; they then start to feed by biting through the skin and sucking blood. They may take three to five days to complete their blood meal, and then drop back into the undergrowth.

Deer Tick (*Ixodes ricinus*)

The peak periods for tick feeding are in late spring and early summer (May - July) and to a lesser extent in the autumn (September - October). There may be a lower risk of tick bites at other times of the year if the weather is mild.

Nymph on thumbnail - actual size

Adult on thumbnail - actual size

Engorged adult female tick after feeding - actual size

Prevention is Best - be tick aware

When in grassy, brushy or woodland areas:

- Keep your skin covered. Wear trousers rather than shorts or a skirt. Tuck your trouser bottoms into socks, and wear shoes or boots rather than sandals. Wear a long-sleeved shirt, with the cuffs fastened. These precautions will keep ticks on the outside of your clothes, where they can be spotted and picked off. Consider using appropriate insect repellents over your clothing and on exposed skin.
- Examine yourself and your children for ticks every three to four hours and at the end of the day. Brush off clothing before going indoors and check that pets do not bring ticks into the home on the fur. Check your skin thoroughly for any attached ticks after returning from a tick-infested area, paying particular attention to skin-fold areas such as the armpits and groins and also the scalp, especially in young children.
- Remove any attached ticks as soon as you can.
- Use veterinary tick and flea repellents or tick collars on pets.
- If you regularly work* in a tick-infested area don't wear your work clothing to go home in.

*Lyme disease acquired through work involving exposure to ticks is a reportable occupational disease under the Reporting of Injuries, Diseases and Dangerous Occurrences Regulations (RIDDOR) 1995.

If you have been bitten...

Don't panic. Remove the tick as soon as possible.

Even if the tick is carrying infection it is very unlikely to transmit it in the first few hours of its feed, so early removal is a very effective prevention measure.

Grasp the tick as close to the skin as possible, using fine tweezers or finger nails, and pull firmly and steadily without jerking or twisting. Don't rush. Try not to squeeze or crush the tick's body. Sometimes, tick mouth parts can break off from the body and remain in the skin. This is unlikely to increase the risk of Lyme disease, but common skin organisms could cause infection. Apply a skin disinfectant once the tick has been removed.

Specially designed tick extractors are available from veterinary practices and pet shops. They are inexpensive and particularly useful for people who are likely to have frequent tick exposure.

Never apply heat, e.g. lighted cigarette ends or match heads, to attached ticks.

Do not use chemicals such as alcohol, nail polish remover, petroleum jelly or aromatic oils to ticks prior to removal. These substances could increase infection risk by stimulating the tick to regurgitate saliva into the bite wound.

Check for redness around the site of the bite. If you are concerned in any way or become unwell, see your doctor as soon as possible.

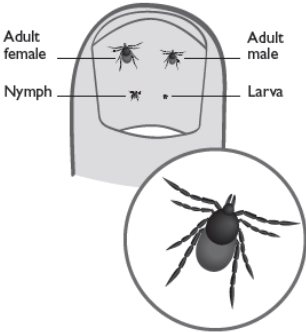
Appendix 22: Royal Parks Leaflet

WHAT ARE TICKS?

Ticks are small creatures related to spiders and mites, that feed on the blood of animals and sometimes people. Ticks can survive in many places but prefer slightly moist, shady areas such as bracken, bushes and leaf litter. They can be found in both long and short grass. Ticks can't jump or fly, so they have to wait until an animal (or human) brushes past to attach to their skin. The tick population peaks between late spring and autumn (April to October).

WHAT DO THEY LOOK LIKE?

Tick nymphs or larvae are about the size of a pin head, flat in shape and ranging in colour from brown to black. Adult ticks are slightly bigger and look like small spiders. When feeding, a tick's body will fill with blood and swell to the size of a match head, becoming purple, blue-grey or pink in colour.



MORE INFORMATION


If you would like to know more about tick bites or Lyme disease visit the following websites:


www.hpa.org.uk

www.nhs.uk/conditions/lyme-disease

www.oeghmp.at/eucalb/


www.cdc.gov/ncidod/dvbid/Lyme/






THE ROYAL PARKS

www.royalparks.org.uk



TICK BITES AND LYME DISEASE



www.royalparks.org.uk

WHAT IS LYME DISEASE?

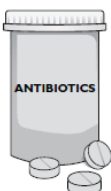
Lyme disease or Lyme borreliosis, is a bacterial infection spread by infected ticks. Human infection is uncommon, because only a small proportion of ticks have the infection. However, those ticks that may carry Lyme disease are common in the countryside, especially woodlands and parks with deer, such as Richmond Park and Bushy Park.

WHAT ARE THE SYMPTOMS?

The early symptoms of Lyme disease develop between 3 to 32 days after receiving a bite from an infected tick. The first sign is often a pink or red rash around the bite site. The rash can gradually spread to form a large circle up to 50cm (20 inches) in diameter, which can be faint or difficult to see on darker skins.

Other symptoms can develop, including flu-like symptoms such as headaches, chills, tiredness, muscle pains, joint aches and fever.

More serious complications may develop weeks or months after an infected bite is untreated. These include temporary facial paralysis, pain, weakness or loss of sensation in the arms, legs or trunk, and arthritis.



Symptoms resolve quickly with antibiotic treatment. Early recognition and treatment is important and will help to prevent the more serious complications from developing.

HOW TO MINIMISE RISK OF INFECTION

The best precaution is to avoid being bitten so follow the adjacent prevention tips. Tick bites don't hurt, so they can easily go unnoticed. When you get home check your whole body for ticks, paying particular attention to your head, neck, skin folds (armpits, groin, backs of knees and waist) and your clothes. Be sure to check along the hairline and neck area, particularly in young children.

WHAT TO DO IF BITTEN


Remove the tick as soon as possible. Using fine pointed tweezers or a tick-removal tool, grasp the tick as close to the skin as possible. To detach a tick, pull upwards firmly and steadily, without jerking or twisting.

- ✗ Don't squeeze or crush the tick's body as this could increase the risk of infection by prompting the tick to regurgitate saliva into the bite wound.
- ✓ After removal of the tick, apply an antiseptic to the bite site.
- ✗ Don't use petroleum jelly, liquid solutions, freeze or burn the tick.

After tick removal, continue to check the bite site over the subsequent month, looking for signs of increased redness or rash. Consult your doctor if any symptoms develop.


Remember to check pets for ticks too!

Ticks like our ears, eyes, chin, muzzle, tail and toes. If you are a regular dog walker in Richmond Park or Bushy Park consider carrying tweezers or a tick removal device in your pocket for rapid removal of the ticks.



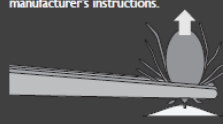
TO PREVENT TICK BITES

- Wear long sleeved tops, trousers tucked into socks and closed shoes, not sandals
- Use insect repellent
- On pets, use tick repellent collars and tick treatments available from your vet
- Stick to paths
- Avoid walking through dense vegetation



TICK REMOVAL

Fine tweezers or a specialised tick remover can be used to remove the tick. The specialised tick removal tool has a flattened hook for effective grip on the tick. They are available for purchase at the Richmond Park Information Centre at Pembroke Lodge and the park office located in Holly Lodge. They are also available at vet practices and online. For proper use follow the manufacturer's instructions.



Appendix 23: Read Aloud Protocol / Discussion Guide

[The following to be read or paraphrased to the participants]

The read aloud protocol is designed to assess whether a text is engaging, clear and understandable. During this task you will be asked to read and respond to a draft information sheet relating to ticks and tick-borne disease.

Steps:

- First I'm going to ask you a few short questions about ticks.
- Next, please read the information sheet to yourself. As you are reading, mark any statement that interests you, surprises you, or that you have not heard before. Feel free to make notes.
- Once you have finished reading the information sheet I will ask you questions about it. Please answer these questions as openly and honestly as possible, as your answers will help us to improve future messages and information.

Preliminary questions:

1. Do you currently practice any behaviours to avoid ticks in the UK? (If yes, what?)
2. Do you think ticks or a tick biting you is disgusting?
3. If you had a tick biting you would you feel confident about removing it?

Questions about intervention:

1. Please provide a summary of the information that you just read.
2. What is your overall impression of the information sheet (e.g. Informative, confusing, easy to use, difficult to understand, etc.)
3. Do you think the information sheet would address any questions or concerns you have about ticks and tick-borne disease? If it doesn't, what additional questions do you have and what information might you wish to see?
4. Do you have any suggestions to improve the information sheet?
5. What do you consider to be key points in the information sheet?
6. Step through the information sheet section by section to identify any further comments on each section.
7. Any comments on preferred presentation styles (including fonts, layout, pictures, headings, etc.)
8. Where would you expect to see this information? (e.g. Leaflet, television, website, etc.)

Final questions:

1. Having seen that information do you think you would now practice any of those behaviour to avoid ticks? (If yes, which ones and why?; If no, why not?)
2. Having read that do you feel like your level of disgust towards ticks has changed at all? (If yes, how?)

3. Having read that has your level of confidence about tick removal changed at all? (If confidence is low, what would make you feel more confident?; If confidence is high, what is it that makes you confident?)

Appendix 24: Pilot RCT Questionnaires

Pre-Intervention Questionnaire

We are a group of researchers from King's College London and the Health Protection Agency, interested in people's opinions about health-related issues. We would like to invite you to take part in a survey about this which should not take longer than 15 minutes to complete.

All of the information we collect in this survey will be kept in the strictest confidence and used for research purposes only. It will not be possible to identify any individual in the results.

The survey involves two stages. The first is this 15 minute questionnaire and the second is another, shorter online questionnaire which you will be asked to complete in approximately 6 weeks time. In order to take part in the study you will need to provide your email address so that we can send you the link to the second stage of the study and so that you can be entered into the prize draw for a chance to win £200. You need to complete both stages of the study to be entered into the prize draw.

I consent to the processing of my personal information for the purposes explained to me. I understand that such information will be treated in accordance with the terms of the Data Protection Act 1998. (tick box to indicate consent)

Background information

1. Have you lived in London for the past 2 years?
 - a) Yes
 - b) No

Participants who select option (b) are ineligible for the study and will be automatically routed to the end of the questionnaire.

2. Have you been rambling or walking in any of the following UK locations during the last 2 years (select all that apply):
 - a. New Forest
 - b. Scottish Highlands
 - c. Dartmoor
 - d. Exmoor
 - e. South Downs
 - f. Thetford Forest
 - g. Lake District
 - h. Yorkshire Moors
 - i. Richmond Park
 - j. I have not been to any of the above locations

Participants who select option (j) are ineligible for the study and will be automatically routed to the end of the questionnaire.

The UK locations listed in the previous question are all places where ticks can be found. When walking in these places it is possible that you could come into contact with ticks and potentially

be bitten. Being bitten by a tick could result in you becoming ill with a tick-borne disease called Lyme disease. The next questions are all about ticks.

3. If you have been bitten by a tick you can safely remove it by (select all that apply):

- a. Pulling off with tweezers
- b. Pulling off with your fingers
- c. Covering with Vaseline
- d. Covering with lighter fluid
- e. Burning off with a cigarette
- f. Waiting for it to drop off itself
- g. Covering it with salt
- h. Other (if other please specify in text box provided)

Behaviour measures

4. Please indicate how often you do each of the following while rambling or walking in the UK locations previously listed (New Forest, Scottish Highlands, Dartmoor, Exmoor, South Downs, Thetford Forest, Lake District, Yorkshire Moors, Richmond Park). For each question, please say whether you do it: never, almost never, about half the time, almost always or always.

- a. When rambling or walking I wear long trousers.
- b. When rambling or walking I wear light coloured trousers.
- c. When rambling or walking I tuck my trousers into my socks.
- d. When rambling or walking I stick to the clear pathways.
- e. When rambling or walking I use an insect repellent on my clothes.
- f. When rambling or walking I use an insect repellent on my skin.
- g. After rambling or walking I check to see if I have any ticks on my body.

Q5 only for participants who answered 'about half the time', 'almost always' or 'always' to Q4 option (g). Participants who answer 'almost never' or 'never' to Q3 option (g) move on to Q6.

5. When checking for ticks, which areas of the body do you check and how? (For each answer select never, almost never, about half the time, almost always or always).

- a. Arms
- b. Legs
- c. Torso
- d. Neck and scalp
- e. Use a mirror
- f. In the shower
- g. Get someone else to help me

Predictor measures (these questions are to be randomly re-ordered for each participant and are not labelled with their predictor variable)

Please indicate whether you strongly agree, agree, neither agree nor disagree, disagree or strongly disagree with the following statements:

Disgust

6. Ticks are disgusting
7. Having a tick biting me would be disgusting
8. I would be disgusted if I had to remove a tick from myself
9. Having a tick biting me would make me feel nauseous
10. I shudder when I think of ticks
11. If I saw a tick near me I would feel a strong instinct to avoid it
12. I would be too disgusted by a tick biting me to remove it myself
13. I would rather not know if I was bitten by a tick

Self-efficacy

14. I am confident that I could check my body for ticks after walking or rambling, if I wanted to
15. If a tick bit me I am confident that I could remove it myself
16. I am confident that I could remember to check my body for ticks after walking or rambling, if I wanted to

Response efficacy

17. Checking yourself for ticks is an effective way of reducing the chance of getting ill after walking or rambling

Perceived control

18. Whether or not I get bitten by a tick when out walking in an affected area would depend on me
19. Nothing I do will affect whether or not I get bitten by a tick when out walking in an affected area

Perceived severity

20. Getting bitten by a tick would have major consequences on my life
21. Developing Lyme disease would have major consequences on my life
22. Lyme disease would be a serious illness for me

Perceived likelihood

23. I am likely to come into contact with ticks when out walking in an affected area
24. I am likely to be bitten by a tick when out walking in an affected area
25. If I was bitten by a tick I would develop Lyme disease
26. If I don't take preventive action, then I am likely to develop Lyme disease

At this stage participants will go to one of the three information versions (this will be a random selection done by the survey programme).

Post-Intervention Questionnaire

The following questions are largely similar to those you have already completed – this is on purpose! We're sorry that this is a bit repetitive, but it's very important for our study so we really appreciate you taking the time to answer the questions honestly.

1. What time of year is there a risk that you could be bitten by a tick (select all that apply):
 - a. Any time of year
 - b. Spring
 - c. Summer
 - d. Autumn
 - e. Winter
2. Which of the following conditions can develop if Lyme disease is left untreated (select all that apply):
 - a. Facial palsy
 - b. Joint pain
 - c. Pain in arms and legs
 - d. Loss of sensation in arms and legs
 - e. All of the above

Behaviour measures

3. Please indicate how likely you now are to engage in each of the following while rambling or walking in the UK locations previously listed (New Forest, Scottish Highlands, Dartmoor, Exmoor, South Downs, Thetford Forest, Lake District, Yorkshire Moors, Richmond Park). For each question, please say whether you plan to do it: never, almost never, about half the time, almost always or always.
 - a. When rambling or walking I will wear long trousers.
 - b. When rambling or walking I will wear light coloured trousers.
 - c. When rambling or walking I will tuck my trousers into my socks.
 - d. When rambling or walking I will stick to the clear pathways.
 - e. When rambling or walking I will use an insect repellent on my clothes.
 - f. When rambling or walking I will use an insect repellent on my skin.
 - g. After rambling or walking I will check to see if I have any ticks on my body.

Q3 only for participants who answer 'never' or 'almost never' to Q2 option (g). Others move to Q4 and then onwards.

4. I will not check for ticks after rambling or walking because (select all that apply):

- a. Takes too much time
- b. I would forget to do it
- c. It would be inconvenient
- d. I don't think I really need to
- e. I don't know how to do a check
- f. No one I know does a check
- g. Other (if other please specify in text box provided)

Intervention feedback (questions randomly re-ordered for each participant)

Please indicate whether you strongly agree, agree, neither agree nor disagree, disagree or strongly disagree with the following statements:

- 5. The information made me feel reassured about ticks and tick-borne disease
- 6. The information increased my confidence about my ability to remove a tick
- 7. The information increased my awareness about ticks and Lyme disease
- 8. I found the information useful
- 9. I found the information clear
- 10. I have enough information about what to do to minimise the risk of being bitten by a tick

Predictor measures (questions randomly re-ordered for each participant and not labelled with their predictor variable)

Please indicate whether you strongly agree, agree, neither agree nor disagree, disagree or strongly disagree with the following statements:

Disgust

- 11. Ticks are disgusting
- 12. Having a tick biting me would be disgusting
- 13. I would be disgusted if I had to remove a tick from myself
- 14. Having a tick biting me would make me feel nauseous
- 15. I shudder when I think of ticks
- 16. If I saw a tick near me I would feel a strong instinct to avoid it
- 17. I would be too disgusted by a tick biting me to remove it myself
- 18. I would rather not know if I was bitten by a tick

Self-efficacy

- 19. I am confident that I could check my body for ticks after walking or rambling, if I wanted to
- 20. If a tick bit me I am confident that I could remove it myself
- 21. I am confident that I could remember to check my body for ticks after walking or rambling, if I wanted to

Response efficacy

- 22. Checking yourself for ticks is an effective way of reducing the chance of getting ill after walking or rambling

Perceived control

- 23. Whether or not I get bitten by a tick when out walking in an affected area would depend on me
- 24. Nothing I do will affect whether or not I get bitten by a tick when out walking in an affected area

Perceived severity

- 25. Getting bitten by a tick would have major consequences on my life
- 26. Developing Lyme disease would have major consequences on my life
- 27. Lyme disease is a serious illness for me

Perceived likelihood

- 28. I am likely to come into contact with ticks when out walking in an affected area
- 29. I am likely to be bitten by a tick when out walking in an affected area
- 30. If I was bitten by a tick I would develop Lyme disease
- 31. If I don't take preventive action, then I am likely to develop Lyme disease

Avoidance concerns

- 32. Knowing more about ticks and tick-borne disease makes me want to avoid the outdoors

Demographics

Please select the appropriate option for each question.

Are you:

Male

Female

How old are you:

Into which of the following categories would you place your total household income from all sources before tax and any other deductions:

Under £10,000
Over £10,000 but less than £20,000
Over £20,000 but less than £30,000
Over £30,000 but less than £40,000
Over £40,000 but less than £50,000
Over £50,000 but less than £75,000
Over £75,000
Don't know
Prefer not to say

Which, if any, is the highest educational or professional qualification you have obtained:

GCSE / O-level / CSE
Vocational qualifications (=NVQ1+2)
A-level or equivalent (=NVQ3)
Bachelor Degree or equivalent (=NVQ4)
Masters / PhD or equivalent
Other
No formal qualifications
Still studying
Don't know

Which one of these ethnic groups would you describe yourself as belonging to?

WHITE – British
WHITE – Irish
WHITE – Any other white background
ASIAN OR ASIAN BRITISH – Indian
ASIAN OR ASIAN BRITISH – Pakistani
ASIAN OR ASIAN BRITISH – Bangladeshi
ASIAN OR ASIAN BRITISH – Any other Asian background
BLACK OR BLACK BRITISH – Caribbean
BLACK OR BLACK BRITISH – African
BLACK OR BLACK BRITISH – Any other background
MIXED – White and Black Caribbean
MIXED – White and Black African
MIXED – White and Asian
MIXED – Any other mixed background
CHINESE OR OTHER ETHNIC GROUP – Chinese
CHINESE OR OTHER ETHNIC GROUP – Any other background
Prefer not to say

Thank you for taking the time to participate in this study. Please keep in mind that we will contact you again in 4 to 6 weeks time with a follow up questionnaire. We would very much appreciate it if you completed it – it is much shorter than the one you have just done and should only take you about 5 to 10 minutes.

At this stage participants are done the questionnaire and will exit the web link. Approximately 6 weeks later they will be contacted by email with a link to the follow up questionnaire.

Follow-Up Questionnaire

Several weeks ago you took part in our study which asked you to answer a variety of questions and had you read through some information about ticks and tick-borne disease. We would now like you to complete the final part of the study which is this short questionnaire – it should take no longer than 5 to 10 minutes.

1. To safely remove a tick you can (select all that apply):
 - a. Pull off with tweezers
 - b. Pull off with your fingers
 - c. Cover with Vaseline
 - d. Cover with lighter fluid
 - e. Burn off with a cigarette
 - f. Wait for it to drop off itself
 - g. Cover it with salt
 - h. Other (if other please specify in text box provided)

2. In the time since the previous survey I have been engaged in rambling or walking in the following UK locations (select all that apply):
 - a. New Forest
 - b. Scottish Highlands
 - c. Dartmoor
 - d. Exmoor
 - e. South Downs
 - f. Thetford Forest
 - g. Lake District
 - h. Yorkshire Moors
 - i. Richmond Park
 - j. I have not been to any of the above locations since the previous survey

Participants who choose option (j) move to Q5, all others to Q3.

Behaviour measures

3. Please indicate how often you practiced each of the following while rambling or walking in the UK since the previous survey. For each question, please say whether did it: never, almost never, about half the time, almost always or always.
- a. When rambling or walking I wore long trousers.
 - b. When rambling or walking I wore light coloured trousers.
 - c. When rambling or walking I tucked my trousers into my socks.
 - d. When rambling or walking I stuck to the clear pathways.
 - e. When rambling or walking I used an insect repellent on my clothes.
 - f. When rambling or walking I used an insect repellent on my skin.
 - g. After rambling or walking I checked to see if I had any ticks on my body.

Participants who answer 'never' or 'almost never' to Q3 option (g) move to Q4, all others move to Q7.

4. I did not check for ticks after rambling or walking because (select all that apply):
- a. Takes too much time
 - b. I forgot to do it
 - c. It was inconvenient
 - d. I didn't think I really needed to
 - e. I didn't know how to do a check
 - f. No one I know did a check

Participants who answered Q4 now move to Q7.

5. Please indicate how likely you are to engage in each of the following the next time you go rambling or walking in the UK. For each question, please say whether you plan to do it: never, almost never, about half the time, almost always or always.
- a. When rambling or walking I will wear long trousers.
 - b. When rambling or walking I will wear light coloured trousers.
 - c. When rambling or walking I will tuck my trousers into my socks.
 - d. When rambling or walking I will stick to the clear pathways.
 - e. When rambling or walking I will use an insect repellent on my clothes.
 - f. When rambling or walking I will use an insect repellent on my skin.
 - g. After rambling or walking I will check to see if I have any ticks on my body.

Q6 only for participants who answer 'never' or 'almost never' to Q5 option (g). Others move to Q7.

6. I do not plan to check for ticks after rambling or walking because (select all that apply):
- a. Takes too much time
 - b. I would forget to do it

- c. It would be inconvenient
- d. I don't think I really need to
- e. I don't know how to do a check
- f. No one I know does a check
- g. Other (if other please specify in text box provided)

Predictor measures (randomly re-ordered for each participant and will not be labelled with their predictor variable)

Please indicate whether you strongly agree, agree, neither agree nor disagree, disagree or strongly disagree with the following statements:

Disgust

- 7. Ticks are disgusting
- 8. Having a tick biting me would be disgusting
- 9. I would be disgusted if I had to remove a tick from myself
- 10. Having a tick biting me would make me feel nauseous
- 11. I shudder when I think of ticks
- 12. If I saw a tick near me I would feel a strong instinct to avoid it
- 13. I would be too disgusted by a tick biting me to remove it myself
- 14. I would rather not know if I was bitten by a tick

Self-efficacy

- 15. I am confident that I could check my body for ticks after walking or rambling, if I wanted to
- 16. If a tick bit me I am confident that I would be able to remove it myself
- 17. I am confident that I could remember to check my body for ticks after walking or rambling, if I wanted to

Response efficacy

- 18. Checking yourself for ticks is an effective way of reducing the chance of getting ill

Perceived control

- 19. Whether or not I get bitten by a tick when out walking in an affected area would depend on me
- 20. Nothing I do will affect whether or not I get bitten by a tick when out walking in an affected area

Perceived severity

- 21. Getting bitten by a tick would have major consequences on my life
- 22. Developing Lyme disease would have major consequences on my life
- 23. Lyme disease is a serious illness for me

Perceived likelihood

- 24. I am likely to come into contact with ticks when out walking in an affected area
- 25. I am likely to be bitten by a tick when out walking in an affected area
- 26. If I was bitten by a tick I would develop Lyme disease
- 27. If I don't take preventive action, then I am likely to develop Lyme disease

Thank you for taking part in our study. As a token of appreciation for your time you will be entered into the prize draw for a chance to win £200. The winner will be contacted by email.

Appendix 25: PHE Tick Leaflet

www.hpa.org.uk/webc/HPA/

www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1317138918897

Get in touch

For more information on British ticks or the Tick Recording Scheme (TRS), please visit our website or email tick@phe.gov.uk

You will also find a TRS recording form on our website, to post with your specimens

Tick Recording Scheme Public Health England
Porton Down SP4 0JG

Public Health England (PHE) is a new health organisation that includes the remit previously held by the Health Protection Agency.
For more details, visit www.hpa.org.uk/Ticks

This document is available in other formats on request.
Please call: 020 8327 7018
or email: publications@phe.gov.uk

Public Health England
Wellington House
133-155 Waterloo Road
London SE1 8UG
www.gov.uk/phe
Twitter: @PHE_uk

PHE gateway number: 2013018
April 2013
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Plain English Campaign
Committed to clearer communication

339

Public Health England

Ticks and your health

Information about tick bite risks and prevention



What are ticks?

Ticks are small, spider-like creatures that feed on the blood of animals, including people. Depending on its development stage, the size of a tick varies. Nymphs are about the size of a poppy seed, while adult ticks look more like tiny spiders.

Where can you find them?

Ticks can survive in many places, but prefer moist areas with dense vegetation or long grass. The species most commonly found on people is *Ixodes ricinus*, more commonly known as the sheep or deer tick. They are usually found in woodland, grassland, moorland, heathland and some urban parks and gardens.

How do you come into contact?

Ticks don't jump or fly, but wait until an animal or person brushes past to climb on. They then bite to attach to the skin and start to feed on the blood. It may take several days to complete their blood meal, before they drop off. Ticks can be found throughout the year, but are most active between spring and autumn.

Main health risks

Ticks can transmit bacteria that cause diseases such as Lyme disease, which can lead to very serious conditions if left untreated. Symptoms of Lyme disease can include a circular rash, fatigue, and muscle and joint pain.

More serious conditions such as viral-like meningitis, facial palsy, nerve damage and arthritis can develop without treatment, so prevention and early detection are crucial. Lyme disease can be treated with a course of antibiotics.

Perform a tick check

Make it a habit to check your clothes and your body regularly for ticks when you're outdoors, and again when you get home. Tick bites may not hurt and you don't always notice you've been bitten, so make sure you thoroughly check yourself, your children and your pets.

Ticks prefer warm, moist places on your body, especially the groin area, waist, arm pits, behind the knee and along hair lines, so look out for anything as tiny as a freckle or a speck of dirt. Take simple steps to avoid coming into contact with ticks:

- Walk on clearly defined paths
- Avoid dense vegetation
- Wear light-coloured clothing so ticks are easier to spot and brush off
- Use repellents such as DEET

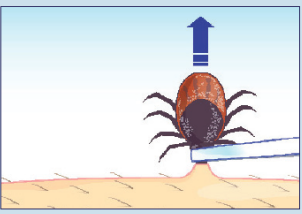
Help us monitor ticks

PHE monitors changes in tick distributions and investigates the drivers for change. Help us monitor ticks by participating in our nationwide surveillance via the Tick Recording Scheme (TRS). You can send in any ticks you come across, which helps us to update our knowledge of British tick species, their spread across the country and detect unusual species.

If you have been bitten

Being tick aware by knowing what ticks look like, where they can be found, and practicing prevention behaviours will help you to avoid tick bites. However, if you do get bitten, removing the tick quickly and correctly can help to reduce any potential risk.

- Remove the tick as soon as possible
- The only safe way to remove a tick is to use a pair of fine-tipped tweezers, or a tick removal tool
- Grasp the tick as close to the skin as possible. Pull upwards slowly and firmly, as mouthparts left in the skin can cause a local infection
- Once removed, apply antiseptic to the bite area and keep an eye on it for several weeks for any changes
- Contact your GP if you begin to feel unwell and remember to tell them that you were bitten by a tick



Appendix 26: Letter of Support



**Public Health
England**

Emergency Response Department
PHE-Porton
Salisbury SP4 0JG

www.gov.uk/phe

Fiona Mowbray
King's College London
Department of Psychological Medicine
Weston Education Centre
Cutcombe Road
London SE5 9RJ

05 June 2013

Dear Fiona,

Re: Your contribution to PHE tick awareness leaflets

This letter is to convey our thanks for your contribution to the development of Public Health England's (PHE) public-facing information concerning the risks from tick-borne disease. These leaflets and fact sheets can be found here:

http://www.hpa.org.uk/webw/HPAweb&HPAwebStandard/HPAweb_C/1317138920210

Your PhD research, which has been co-funded by Public Health England and King's College London, has provided important insights that have helped us to develop our understanding of the public's knowledge, beliefs and behaviour concerning ticks and tick-borne disease. The outcomes from your studies that highlight the protective behaviours that are most amenable to change in members of the public who visit areas where ticks are prevalent are of particular importance for how PHE communicates about these risks.

I am aware that you have co-authored, along with the Medical Entomology & Zoonoses Ecology and Communications teams the leaflets and fact-sheets that are now on the PHE website. These materials have benefited directly from your research and expertise. Notably this information was referred to recently by the BBC news website shortly after Lyme Disease Awareness Week this year.

Thank you again for your on-going contributions to the work of PHE.

Yours sincerely

Dr John Simpson
Head of Emergency Response Department/
Director of Emergency Preparedness, Resilience and Response (Interim)
E john.simpson@phe.gov.uk